Volume I: Research component

Spousal Relationships in Dementia Care

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Overview

This work was completed as part of a three year Doctorate in Clinical Psychology at the University of Birmingham, UK. This thesis is in two volumes. Volume one consists of the research component and the second represents the clinical work conducted on placements within the NHS.

Volume I consists of three papers. Paper one is a critical review of the current literature regarding instruments used to measure relationship quality between a spousal couple when one of the couple has a diagnosis of dementia. Paper two presents the construction and validation of a new measure: The Birmingham Relationship Continuity Measure (BRCM). The final paper of Volume I is an executive summary of the main research findings.

Volume II includes five clinical practice reports. The first report presents the case of 'Mia', who was experiencing low mood. Mia's problems were formulated from both a cognitive and psychodynamic framework. The second report is a single case experimental design, investigating the effectiveness of Cognitive Behavioral Therapy used with a 35 year old man experiencing Obsessive Compulsive Disorder. Report three is an evaluation of a Child and Adolescents Mental Health Services use of outcome measures. The service was evaluated inline with government policy and recommendations made as to how the service could improve the completion of the necessary outcome measures. The final written report is a case study of the work conducted with 'Kate' an older person with anxiety. The fifth clinical practice report is presented here in the form of an abstract, and describes the presentation of a commissioning report for a new service supporting parents with Learning Disabilities.

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Paper 1

A systematic evaluation of measures used to evaluate spousal relationships in dementia care.

Gemma Fisher 2010

Abstract

This review was undertaken to ascertain and evaluate the instruments that have been used to measure spousal relationships when a spouse cares for a partner who has dementia.

A systematic search of four databases identified nine measures that had been used to assess the quality of the marital relationship when caring for a partner with dementia. The information given about each measure's reliability and validity was evaluated as well as the accessibility of the measure to the user, the sample used in generating the measure and the measure's generalisability.

From the nine measures reviewed the conclusion was drawn that the measures used to assess relationships in spousal dementia care are lacking in reliability data and information regarding validity. There also appeared to be great variability regarding how to define the overall construct of relationship quality and many of the measures did not have a theoretical underpinning.

Keywords: dementia, carers, measures, spouse, relationship.

This review highlights some of the reasons why researchers may want to measure the quality of spouse relationships, following which criteria will be put forward for judging the quality of such measures. Measures that have been used to assess the quality of spousal relationships while caring for a partner that has dementia will then be critically reviewed and conclusions drawn.

When one person in a relationship develops dementia, there are inevitable changes in the way that the couple interacts. Over time, one person takes on the caring role as the other gradually becomes more dependent on support (Garand et al., 2007). Wright (1991) conducted a qualitative study with 30 couples where a diagnosis of Alzheimers Disease (AD) had been made. She found differences in the experience of marriage between partners with dementia and relatively healthy couples, particularly in handling tension and expressing negative emotions without upsetting the other. Gallagher-Thompson et al. (2001) videotaped 27 wives and their husbands who had a diagnosis of AD completing two set tasks at home. The tasks included eating a meal together and completing a planning exercise. The findings were compared to the interactions with healthy couples who were of a similar age and had been married for a similar length of time. The results suggested that wives dealing with AD in their relationships were less interactive with their spouses when completing both tasks. Husbands with AD and their wives were also less likely to share ideas and the language used was simpler compared to the couples where AD was not present. Gallagher-Thompson et al. (2001) also found that caregiving wives were more psychologically distressed than their non caregiving counterparts.

As suggested by Gallagher-Thompson et al. (2001), some of these changes can have a negative impact on the wellbeing of the carer and the person with dementia. Morris, Morris and Britton (1988) explored 20 spousal caregivers' views on the level of intimacy in their relationships, before and after the onset of dementia and found that caregivers who reported low levels of intimacy before and after the onset of dementia had higher levels of depression and strain in their caring roles. De Vugt et al. (2003) also investigated deterioration in the marital relationship and found that out of 64 spouses interviewed, it was the apathy of the spouse with dementia that had the biggest effect on the functioning of the relationship. They found that this adversely affected the degree of reciprocity and had a negative effect on communication.

Couples do, however, differ in terms of how well they adjust to the changes in interaction associated with dementia and some are able to maintain the quality of their relationship or even strengthen it. Garland (2007) suggests that couples who maintain positive interactions through communication or personal contact, benefit from increased emotional wellbeing. Quinn et al. (2009) discuss in their paper that partners may feel responsible for one another's well being and support each other. The level of support from a spouse could affect the carer's sense of relationship satisfaction and quality and thus, when judging the quality of couple relationships, it is important to gather data from or about both partners where possible. Murray et al. (1991) found that feelings of mutual affection and warmth can increase following the onset of dementia. Using semi structured interviews, Hellstrom et al. (2007) explored the views of spouses with dementia and found that they described trying to "hold on" and "maintain involvement" within the relationship.

The duration and quality of the past relationship could have an effect on the caregiving relationship. In a questionnaire based study of 72 co-resident dementia carers, 61% of whom were spouses, Steadman et al. (2007) examined the influence of past relationship satisfaction on current family functioning and caregiver burden. They found that carers' ratings of the quality of the prior relationship were significantly linked to current carer burden and a number of aspects of functioning. Carers who rated the past relationship more positively reacted less stressfully to memory and behaviour problems; communicated more effectively with the person with dementia and had better problem solving skills. Whilst this implies that prior relationship satisfaction may have an important influence on carer functioning, it is important to note that carers were asked to look back on their marital relationships in order to rate them and their memories may have been distorted or biased by their current caregiving experiences.

Given the centrality of the spousal relationship in dementia care, then in order to investigate further the positive and negative impact of changes in interaction, as well as the moderating effect of a strong relationship and other factors, it is important to have good measures of the spousal relationship in dementia.

Aim

The aim of this review is to offer a critical analysis of the measures that have been used in research for assessing the spousal relationship in dementia. The focus will be on the generic aspects of the relationship between spouses (i.e. aspects that are common to all close relationships, such as communication, trust and satisfaction with the relationship) and will thus not include measures that centre directly on the caring role itself, such as measures of caregiver stress or burden. There are numerous measures about

caring and aspects of relationships that are specific to the caring role (see for example Burden Interview, Zarit et al., 1980; and the Caregiver Strain Index, Robinson, 1988). Deeken et al. (2003) reviewed 25 self report instruments that measure burden and the needs and quality of life of informal caregivers, including spousal and other carers. However, there are far fewer measures that have been used with couples with dementia that address the generic aspects of relationships. This literature review will therefore concentrate on those instruments that measure such generic aspects.

Approach to judgements of quality

The measures will be systematically reviewed in terms of both quantitative evidence and qualitative observations about their psychometric properties. Evidence of the psychometric characteristics, outlined and defined below, will be searched for in the relevant papers.

Validity

Validity is concerned with whether an instrument measures what it is intended to measure. This is often difficult to assess in the context of psychometric tests but an attempt can be made to establish a number of different aspects of validity. Kline (2000) defines concurrent validity, face validity and construct validity and highlights the importance of each. Goddard and Villanova (2006) also describe divergent and predictive validity. However, the main forms of validity relevant to this review are concurrent, content and construct validity, since these three forms of validity are key and can be confidently determined. An outline of the types of validity can be found in Table 1.1.

Table 1.1. Types of validity common to psychological measures.

Type of validity	Description	How it is evaluated
Face	A test has face validity if it appears to measure what it claims.	Qualitatively evaluated, by examining whether the items in the measure look as if they measure the overall concept.
Content	If the content of the measure addresses the target concept.	Evaluation of the items. Content validity can only be achieved if the measure has specific, definite knowledge.
Concurrent	The correlation of the developed instrument with a benchmark measure to test that the developing measure is measuring the concepts it purports to.	Requires the use of a benchmark measure with reliability and validity to correlate with the developing measure. High correlation suggests a measure with high concurrent validity.
Discriminant	The extent that a developing instrument correlates with an existing instrument designed to measure theoretically different concepts.	Correlation is calculated between the developing measure and an existing measure, which has a different theoretically underpinning. To have discriminate validity these measures should not correlate.
Construct	The extent to which the measure can be demonstrated to appropriately assess predictions based on a theoretical framework.	By having hypothesis about how the new measure should behave with regards to the theoretical underpinning.
Predictive	A measure has predictive validity if it can successfully forecast a future outcome.	Correlation between the measure and a later predicted outcome.

Concurrent validity is a way of measuring the extent to which the concepts of the developing measure are consistent with other measures purporting to assess similar concepts. A legitimate and valid way of measuring concurrent validity is to measure the correlation between the developing questionnaire and another existing questionnaire purporting to measure the same variables, which has already produced valid and reliable data. Measures that have followed this procedure and reported a positive correlation have a strong concurrent validity. On a similar note, a measure is described as having divergent validity if the correlation between the newly developed measure and a measure of a construct that is conceptually distinct from the new one are statistically significantly different.

Construct validity is associated with clarifying the concept that will be measured by the developing instrument. When establishing the construct validity of a measure, it is important that a measure relates to a clear theoretical framework and that the constructs being measured are clearly defined in terms of that framework. If a measure is based on a strong body of evidence, the chance of achieving construct validity is increased. Once a clearly defined framework is produced, a set of hypotheses concerning the scores of the measure should follow. If the findings of the test support the hypotheses, then the test has good construct validity. Leong and Austin (2006) suggest that the employment of construction specification is lacking in the literature pertaining to measure development.

Evaluating validity

The review will evaluate the validity of the measures by referring to both quantitative and qualitative aspects. The qualitative evaluation will involve an analysis of the questionnaire in terms of factors that may undermine its validity, since if a measure does

not meet the criteria shown below, it will not be able to tap answers which provide a valid assessment of the construct. This will include consideration of:

- complexity or the use of jargon;
- ambiguity or lack of clarity in wording or instructions;
- the relevance of the items to what the questionnaire is intended to measure;
- the intrusiveness of the items (since people may be unwilling to answer them honestly or unwilling to answer them at all);
- the likely influence of response sets, such as social desirability (answering in a way that puts them in a good light, rather than answering honestly) and acquiescence (the tendency to answer 'yes' to everything).

A useful way of obtaining information about these potential influences on validity is to seek, during the development of the questionnaire, the opinions of people drawn from the population for whom the questionnaire is intended. Therefore in the review of the measures, it was noted whether the development of the questionnaire involved such consultation.

Reliability

Two forms of reliability are important in determining whether a questionnaire has good psychometric properties (Goddard & Villanova, 2006). The first of these is internal consistency, which indicates the extent to which the items are measuring the same underlying construct or whether the test is self consistent. Internal consistency is commonly calculated using Cronbach's coefficient alpha (symbolised as α; Cronbach & Shavelson, 2004). Throughout this review, a Cronbach's alpha of .7 and above will be considered an acceptable level of reliability (Goddard & Villanova, 2006).

Factor analysis can also be used to establish internal consistency. If the assumption is that the scale is measuring a one-dimensional construct, then all items would be expected to load highly on one factor which should explain a large amount of the variance in the scores. Factor analysis can also be used to verify assumptions that there are subscales within the overall scale, by looking at which items correlate most highly with each other. A factor analysis however does require large sample sizes.

The second index of reliability of interest is whether the test yields the same scores when it is used on more than one occasion. This is known as test re-test reliability. This is achieved by asking the participants to complete the same questionnaire twice, with a lapse of time between the two administrations. Thorndike (1997) suggests that the reliability can be determined by calculating the correlation of the two sets of scores. Pedhazur and Schmelkin (1991) suggest that a time lapse of one to two weeks is acceptable.

Without demonstrated test-retest reliability, any change in scores could be the result of extraneous factors, such as fluctuations in mood or fatigue, rather than due to a change in the underlying construct that is being measured. The test-retest procedure offers confidence that the measure produces more or less the same result each time it is administered, unless the underlying construct has genuinely changed or it is affected by the mood of the participant or other external factors.

User acceptability

The measures will also be evaluated for additional issues such as the likelihood of a respondent completing the overall measure and individual items. Respondents may be less likely to complete a measure if the items are intrusive, taxing or likely to elicit an

acquiescent response. The length of the measure may also influence overall user acceptability.

Sample

In using a questionnaire, it is important to identify the limits of the psychometric data and thereby to whom it can appropriately be administered. A questionnaire that is valid and reliable for one group of people may not be valid and reliable for another. For example, a relationship questionnaire validated for use with young couples in their twenties may not be valid when used with couples in their seventies. With this in mind, it is important in the evaluation of the quantitative data to consider the samples used to establish reliability and validity.

The appropriateness of the sample on which the questionnaire was developed will be gauged to establish whether this is representative of the intended population. This will be judged from the information given on key demographic variables such as the participants' age and gender. Each measure in this review will need to have been used on a representative sample of a clearly-defined population, for example the measure should have been used with a sample of spouses caring for people with dementia.

To evaluate the questionnaire in this respect, consideration will be given as to whether the population is clearly defined and whether the recruitment strategy employed is likely to have resulted in a representative sample. The sample size used in the development of the measures will also be evaluated. This is important, as the smaller the sample, the less likely it is to be representative of the population under investigation**.**

During item construction, potential cultural and gender influences should also be considered, for example the expectations of female and male roles in the relationship and

their possible effects on responses to certain questions. The items in the measure will also be evaluated in terms of whether the questions make reference to specific cultures. Items that make reference to specific cultural ideas, values or practices could mean that the questionnaire's validity would be undermined if it were given to people who were not from that culture. In the qualitative evaluation of the questionnaires, the items will be considered in terms of whether their content is likely to be specific to certain populations defined by age, culture and gender.

Method

Search Criteria

The terms in Figure 1.1 outline the criteria for the primary search for articles that was conducted using the databases Web of Science, Ovid's Medline and PsychInfo, between the years 1987 and 2009. Only peer reviewed journal articles published in the English language were included.

(measur* OR assess* OR question OR instrument*) AND (psycholog*) AND ("dementia" OR "Alzheimer's") AND "relationship* satisfaction OR relationship* quality") AND (spouse* OR partner* OR husband* OR wife* OR wive* OR couple* OR Marriage*)

Figure 1.1 Search terms used in present review

As the search terms indicate, the preliminary goal was to identify psychological research measuring the relationship quality of couples in dementia care. The initial search resulted in 233 research papers. Inclusion and exclusion criteria were then applied to the 233 articles. Papers were included if they were in English, used a measure of the generic relationship between spouses and the sample included people who were in a spousal relationship in which one of the partners had dementia. Throughout this review, the term

spousal relationship includes couples or partners who are married or who co-habit and are in a ‘romantic relationship’ rather than the relationship between a parent and child, siblings or friends.

From the 233 initial references, five papers met the search criteria. The reference sections of each of the five articles were then scrutinised and four further measures were identified for inclusion, making a total of nine measures for review. These are shown in Table 1.2 and each is described and evaluated below.

Table 1.2: Basic details of the measures being reviewed.

Measure	**Measure used in dementia care**	**Original source**	**Items**	**Sample size in measure development**	**Context in which measure was originally designed**	**Concepts**	**Psychometric properties** (taken from original source, unless otherwise stated)
The General Atmosphere, Happiness in Marriage Questionnaire	Eloniemi-Sulkava, et al. (2002)	Designed for paper	7	N = 42	To explore the effects of dementia on the general atmosphere and happiness in martial relationships.	Happiness	Test retest (not available) Internal consistency (not available). No validity data available
BRSS Relationship Satisfaction Scale (BRSS)	Stedman et al. (2007)	Burns & Sayers (unavailable)	7	Not available	Not available	1.Communication 2. Openness 3. Conflict resolution 4. Caring & affection 5. Intimacy & closeness 6.Satisfaction with roles.	Test-retest (not available) Internal consistency (not available) Inter-scale correlation (not available) No validity data available
Intimacy Questionnaire	Morris, Morris & Britton (1988)	Designed for paper	24	N = 20	To explore the quality of the marital relationship in spousal dementia care.	1. Affection 2.compatibility 3. cohesion 4. conflict 5. expressiveness 6. resolution 7. sexuality 8. Identity	Test-retest (not available) Internal consistency α= 0.96 No validity data available

Mutuality Scale	Gallagher-Thompson et al. (2001)	Archbold et al. (1990)	15	Not available	Not available	1. Shared values 2. Affective closeness 3. Shared pleasurable activities 4. Reciprocity	Test-retest (not available) Internal consistency α = .91 (Gallagher-Thompson et al. 2001) No validity data available
Measurement of Positive Affect	De Vugt et al. (2003)	Mangen, Bengtson Landry (1988)	4	N = 53	To investigate the relationship interactions between three different generations.	1. General closeness 2. Communication 3. Similarity of views 4. Degree of getting along.	Test –retest (not available) Internal consistency α = .73 (De Vugt et al. 2003) No validity data available
Family Adaptability and Cohesion Evaluation Scale –III (FACES)	Rankin, Haut and Keefover (2001)	Olson (1986)	20	Not available	FACES-III was developed for the purpose of gathering information to construct a model of family relations.	1.Cohesion 2.Ability to change 3.Communication	Overall consistency α = .68 cohesion α = .77 adaptability α = .62 (Olson, 1986) No validity data available
Dyadic Adjustment Scale (DAS)	Wright (1991)	Spainer (1976)	32	N =218	Designed to measure the quality of marriage and similar dyads for research purposes.	1. Consensus 2. Satisfaction 3. Cohesion 4.Affection	Consensus α = .90 Satisfaction α = .94 Cohesion α = .86 Affection α = .73

Closeness and Conflict Scale	Schofield et al. (1998)	Schofield et al. (1997)	6	N = 946	Designed to report the experience of caregiving, and social and emotional wellbeing.	Closeness: 1. Compassion 2. Love 3. Closeness Conflict: 1. Conflict 2. Tension 3. Resentment	Has good construct, content and criterion-related validity. Closeness α = .68 (1993) α = .73 (1994) Conflict α = .70 (1993) α = .75 (1994) Good construct validity.
Quality of Prior Relationship (QPR)	Kramer (1993)	Williamson and Schulz (1990)	14	N = 174	Designed to measure the quality of prior relationships on caregiver outcome.	1. Communication 2. Affective expression 3. Involvement	Internal consistency α = .87

General Atmosphere, Happiness and Relations in Marriage Questionnaire

Description of the measure

This questionnaire was developed by Eloniemi-Sulkava et al. (2002). It was designed specifically for their study and does not appear to have been used in any further published studies. There are seven items in total 1) "What was/is the general atmosphere in your marriage?" 2) Which option describes best the degree of happiness in your marriage?" 3) "What were/is mainly your relations in marriage?" 4) "How well did/does your spouse fulfil your expectations as a spouse?" 5) "Did/does your spouse express disturbing jealousy?" 6) "Was/is your spouse used to expressing sexual needs in your marriage?" 7) "How important was/is the sexual relationship in your spouse life?"

Participants are asked to rate their relationship with their spouse before and after the onset of dementia using a five point Likert scale. The options of response change depended on the item, for example 'perfectly happy – very unhappy'; 'extremely warm-hostile'. There is no mention of how the questionnaire is scored, though this can be surmised.

Quantitative evaluation

The questionnaire was developed in the context of a study that investigated changes in the spousal relationship when a partner receives a diagnosis of dementia. The total number of participants was 42 (29 wives and 13 husbands), with a mean age of 72 years. Participants were recruited in Finland via a previous study conducted by Eloniemi-Sulkava et al. (1997). Participants were caring for spouses who had a diagnosis of dementia but the duration of their caring roles was not stated. Information was also not provided regarding the level of support the carer received or the severity of the spouse's dementia. Not having information on the nature of the sample prevents a judgment about

the suitability and generalisability of the questionnaire being made. There may also be cultural differences to consider as the sample was recruited in Finland where people may have different cultural views with regard to relationships compared to spousal carers in the UK. The sample size of 42 suggests that caution should be exercised when using this measure, as the sample is not big enough to be representative. Reliability and validity data are not reported and the methodology does not clearly suggest how the items were generated. There is also no information about seeking feedback about the questionnaire from the population for whom the questionnaire is intended.

Eloniemi-Sulkava et al. (2002) discuss using statistical analysis to create three categories of outcome: "positive change", "no change" and "negative change" to indicate whether change has occurred in the relationship since the onset of dementia. However, replication of these categories would be difficult, as no information is given about the cut off points of each category. There is also no information about how to score the measure, thus making it difficult to replicate and to draw any conclusions about the quality of the relationship.

Qualitative evaluation

Some of the terms used in the questionnaire are unclear and the definitions of the terms are not provided, for example the term 'general atmosphere' could be interpreted in many different ways. This item may have benefited from having a definition of what was meant by 'general atmosphere'. There also appear to be no clear hypotheses as to how or why particular items were generated. The use of a retrospective measure of the relationship prior to the development of dementia may be particularly vulnerable to response bias because of the tendency of people to have distorted views of their past life

together (Kline, 2000), although it is acknowledged that prospective studies are difficult to conduct.

On the positive side, the questionnaire is relatively short and would not take too long to complete, which adds to its appeal and enhances user acceptability. Nevertheless, the items could easily distress participants and asking directly about the sexual nature of the marriage could be embarrassing and/or intrusive for participants.

In summary, this measure lacks adequate data about the sample, together with reliability and validity for use with spousal caregivers for partners with dementia. There also appears to be a lack of theory behind its development.

Burns Relationship Satisfaction Scale (BRSS)

Steadman, Tremont and Duncan-Davis (2007) investigated the association between the premorbid relationship and caregiver burden. They measured the premorbid relationship using the Burns Relationship Satisfaction Scale (BRSS) developed by Burns and Sayers (unpublished and unavailable manuscript).

Description of the measure

The authors describe the BRSS as a seven-item self report inventory, with each item tapping into a different area of relationship satisfaction. These include: communication, openness, conflict resolution, degree of caring and affection, intimacy and closeness, satisfaction with roles in the relationship, and overall relationship satisfaction. Each item has a six point Likert response scale ranging from "very dissatisfied" to "very satisfied". The BRSS is scored by adding the total of the items (range 0 to 42) - the higher the score, the greater the level of satisfaction. In addition to being used in Steadman et al.'s study, the BRSS has also been used to measure satisfaction in sibling relationships (Gronewold, DeGreeff & Semlak, 2008). However, to

data the BRSS has not been used to assess spousal relationships in any other published study.

Quantitative evidence

According to Steadman et al. (2007), the original study (Burns & Sayers, unpublished manuscript) reported satisfactory reliability (alpha = .94) and validity (correlation between the BRSS and the Dyadic Adjustment Scale of -0.89). It is difficult to evaluate this evidence because the original paper is unavailable. Without knowing the composition of the sample used in the original paper, it is unclear whether the high reliability and validity reported in this paper would apply when the measure is given to spousal carers looking after someone with dementia. Unfortunately, Steadman et al. (2007) do not report any reliability or validity data relating to their own sample.

Qualitative evaluation

The Steadman et al. (2007) paper does not offer information about any theoretical framework used to develop the questions or about how or why the particular constructs were chosen. Moreover, there is no information about user feedback. As the BRSS is not available, a detailed qualitative evaluation cannot be conducted.

Overall, this measure lacks adequate data about its reliability and validity for use with older people generally and specifically for use with dementia caregivers.

Intimacy Questionnaire

Morris, Morris and Britton (1988) developed the intimacy questionnaire for the purpose of measuring the quality of relationships between spousal caregivers. Although their study is very widely cited study, the questionnaire itself does not appear to have been used in any further studies.

Description of the measure

The intimacy questionnaire consists of 24 statements covering eight areas of intimacy, (affection, cohesion, expressiveness, compatibility, conflict resolution, sexuality and autonomy/identity). The response is a five point Likert scale from 'strongly agree' to 'strongly disagree'. Examples items given are: "The feelings I have for my partner are warm and affectionate" and "My partner is critical of the decisions I make" but the whole measure is not contained in the paper and is not readily available. The total estimated change of intimacy in the relationship is calculated by subtracting present intimacy scores from perceived past scores.

Quantitative evidence

Overall 20 spousal co-resident caregivers completed the questionnaire (13 wives and seven husbands). The average age of the caregivers was 68 and they all cared for spouses who had a diagnosis of Alzheimer's or vascular dementia. The average duration of the dementia was 46.2 months.

The size of the sample is relatively small (20), increasing the chance that the sample may not be representative. Participants were self selected and recruited in the North East of England via voluntary dementia organisations. Recruiting from a voluntary organisation limits the generalisability to the wider population of spousal carers.

Morris, Morris and Britton (1988) do not reveal the methodology employed for the development of the intimacy questionnaire. It is therefore difficult to comment on the methodology and any statistical analysis used in its development, for example the use of a focus group or coefficient reliability in the item construction. It is reported that the items were generated from a working operational definition of intimacy suggested by Waring and Patton (1984) but this definition is not described.

Morris, Morris and Britton (1988) provide no evidence about validity. With regard to reliability, they report a split-half reliability coefficient (r = .96) using the Spearman-Brown formula. Split-half is an alternative statistic that can be used to test for reliability. Although it is not considered as sophisticated as the use of Cronbach's alpha coefficient, the very high level implies good internal consistency.

Qualitative evaluation

Morris, Morris and Britton (1988) present one example item for each of two of the eight factors suggested by the authors to define intimacy (affection and conflict resolution) but the other 22 items are not presented, making it difficult to review the validity of the items for each area and other qualitative qualities such as readability or the use of jargon. However, the length of the intimacy questionnaire (22 items) appears to be acceptable.

Overall the intimacy questionnaire is a reasonable sized questionnaire that has a theoretical basis, has been validated with spouse carers in dementia and appears to have good reliability. The questionnaire may benefit from further validation with a bigger sample of spouse carers.

Mutuality Scale

Gallagher-Thompson et al. (2001) used the Mutuality Scale developed by Archbold et al. (1990) to measure the differences in social interactions between husbands and wives where the husband had a diagnosis of dementia and a comparison group where the husband did not have such a diagnosis. The Mutuality Scale has also been used in a number of other studies, including with spousal carers whose partners have physical health problems such as heart bypass surgery (Kneeshaw, Consdine & Jennings, 1999); with family caregivers following bone marrow transplants (Eldredge, Nail, Mazlaz,

Hansen & Archbold, 2006) and with family caregivers for people with chronic physical conditions (Capezuti, Zwicker, Mezey & Fulmer, 2008).

Description of measure

The Mutuality Scale consists of 15 items. The items in the scale are reported to measure: shared values, affective closeness, shared pleasurable activities and reciprocity. The response scale is a four point Likert scale, where a score of one is given for "none" or "not at all" and a score of four is given for "a lot" or "a great deal". The scores are totalled and divided by 15 to give an overall score between 1-4. The higher the overall score, the more mutuality in the relationship. Some examples of the items in the mutuality scale include: "To what extent do you and she/he see eye to eye?" How attached are you to him/her?" and "How close do you feel to him/her?"

Quantitative evidence

Gallagher-Thompson et al. (2001) present data regarding reliability of the Mutuality Scale. The Cronbach's alpha coefficients for the four constructs of the Mutuality Scale are: shared values (α = .73); affective closeness (α = .90); shared pleasurable activities (α = .89) and reciprocity (α =.89). The alpha level for shared values suggests that this construct has less internal consistency but still at an acceptable level. The alpha coefficients are not based on Gallagher-Thompson et al.'s (2001) data and the source of these coefficients is not referenced. The primary reference for the Mutuality Scale given by Gallagher-Thompson et al. (2001) is Archbold et al. (1990) but this paper does not present the original data. It is therefore not possible to define the sample on which the alpha coefficients are based and therefore it is uncertain whether the same level of internal consistency is likely to have been achieved by Gallagher-Thompson et al. in their study of spousal carers in dementia. However Gallagher-Thompson et al. have used

an American sample, raising the possibility that the results may not generalise to a UK population.

Gallagher-Thompson et al. (2001) do not present any validity data for the Mutuality Scale. There is also no information presented about any theoretical framework being a basis of the scale. Gallagher-Thompson et al. (2001) suggest that mutuality is an operational term referring to several aspects of marital satisfaction. However, as the information regarding construction of the mutuality scale is not available from Archbold et al. (1990), the validity of the scale in this respect is difficult to evaluate.

Qualitative evaluation

Some of the 15 items that make up the Mutuality Scale could be interpreted as ambiguous. For example, in the item: "How attached are you to her/him?" the word 'attached' could be seen as emotional, financial or physical by participants. Moreover, items such as "How much love do you feel for her?" may cause participants to answer in a socially desirable way. Nevertheless, the scale's length makes it manageable for respondents.

In summary, there is not enough information presented on the mutuality scale in Gallagher-Thompson et al.'s (2001) paper to evaluate the suitability of its use for spousal carers. However, this scale has also been used to assess caregivers' relationship satisfaction in a number of other studies and so psychometric data for its use are gradually accumulating.

University of Southern California Longitudinal Study of Three-Generation Families

Measures of Positive Affect

De Vugt et al. (2003) used the above measure constructed by Mangen, Bengtson and Landry (1988) to investigate the relationship between behavioural disturbance and the quality of the marital relationship in dementia. The questionnaire was used to rate the current quality of the relationship from the perspective of spousal carers who were then asked to rate on a scale of one to four the change in their relationship prior to the diagnosis.

Description of measure

The measure has four items used to measure four constructs of relationship quality. The four constructs and their related items pertain to how well the couple generally get along ('How well do you get along with your partner?'); communication ('How is communication in the relationship?'*);* similarity between views ('How similar are your views?') and an overall assessment of the perceived closeness in the relationship ('How close do you feel?'). Responses are given on a six point scale from 'not at all *close/well/similar' to* 'very *close/well/similar'*. As well as quantifying the quality of the relationship in dementia care, this measure has also been used to investigate the impact on caregiver's quality of life in those caring for a relative who has had a stroke (White, Poissant, Cot-LeBlanc and Wood-Dauphine (2006). As in dementia, those with stroke are usually an older population. However, since White et al's sample of carers was not confined to spouses, their study cannot be directly transferred to the present context.

Quantitative evaluation

The participants in the original paper Mangen, Bengtson and Landry (1988) were part of a larger study measuring intergenerational cohesion between three generations:

grandparents (mean age 67); parents (mean age 44) and grandchildren (mean age 22) There were no comparisons made within generations, thus the four items have not been developed for use between couples in the same generation. The original paper also presented no evidence about validity.

De Vugt et al. (2003) provide data about reliability within their sample of spousal carers looking after a partner with dementia. De Vugt et al. (2003) present internal consistency of α. = .73, suggesting adequate internal consistency. De Vellis (2003) reports that the larger the number of items within a measure the less prone a measure is to change in reliability with a new sample. Thus, this scale may be vulnerable to fluctuatating reliability rates with different samples, given it only has four items.

The sample used in De Vugt et al.'s (2003) paper consisted of 22 husbands and 31 wives with a mean age of 68.3 (*SD* = 7.9). The research was conducted in Maastricht (Netherlands) and spousal caregivers were recruited via the hospital's memory clinic. The study may not truly reflect spousal caregivers due to the small sample size (N = 53). The generalisability of the measure to the UK may also be problematic due to specific beliefs and attitudes regarding dementia and caregiving that may be held in the Netherlands and the original American sample.

Qualitative evaluation

All four items are worded in a very general way and this could give rise to different interpretations. For example, "How similar are your views?" does not specify what views are being referred to and different people may interpret this in different ways. The item regarding communication ('How is communication in the relationship?') could be difficult to answer for some respondents, as there are many different ways of

communicating, for example, verbal communication may be less effective than before the diagnosis of dementia but non-verbal communication may have improved.

The length of the scale (N = 4) makes the University of Southern California Longitudinal Measure of Positive Affect appealing for use and data presented by De Vugt et al. (2003) suggest that this could be a useful measure of relationship with a caregiving spouse but more research would need to be conducted with a larger sample to provide better evidence about its reliability and validity.

Family Adaptability and Cohesion Evaluation Scale –III (FACES)

Rankin, Haut and Keefover (2001) used FACES to measure marital cohesion and satisfaction as part of constructing a model of spousal caregiving in the context of dementia.

Description of measure

The FACES-III (Olson, 1986) is a 20 item instrument with a 1 to 5 response scale (1= almost never, 5= almost always). It is designed to measure cohesion, ability to change and communication. The instrument can be used for both family and couple relationships. The questions are administered twice - once to assess the current perceived view of the relationship and a second time to capture the respondent's ideal relationship with the same person. Example items include: "We ask each other for help"; "We like to spend free time together". The FACES III yields two scores: cohesion and adaptability. The weighting of the scores is even, with both constructs having 10 items. The higher the cohesion, the more enmeshed and close is the relationship. The higher the adaptability, the more chaotic and distant is the relationship.

According to a textbook which surveys measures for use with families and carers (Fischer & Corcoran, 2007), the FACES-III instrument has been extensively used in a

range of studies with a total of almost 2,500 participants. Research where the FACES-III has been used to measure the quality of relationships in physical health conditions between spouses include chronic pain (Roy & Thomas, 1989) and spouses who care for their significant other who has palliative cancer (BrintzenhofeSzoc, Smith & Zabora, 1999). The differences between caring for a partner with a physical condition such as pain or cancer may impact on the couple's relationship in a different way to caring for a partner who has a degenerative condition such as dementia. However, there does appear to be accumulating data on the use of FACES-III within the spousal caring relationship.

Quantitative evaluations

According to the original source (Olson, 1986) the overall alpha level was .68. The alpha level for cohesion was .77 and .62 for adaptability. These scores demonstrate quite low reliability overall and particularly for adaptability. In the development of the measure, there appears to be re-test data, suggesting good stability r = .83 for cohesion and r =.80 for adaptability (Fischer & Corcoran, 2007). However, Rankin et al. (2001) do not report any reliability or validity statistics based on their own data.

In terms of validity, there is a theoretical basis underlying the FACES-III as it was constructed to measure the functioning of families and couples in line with a circumplex model (Oslon, Portner & Lavee, 1985) that there are three central dimensions of family and couple functioning: cohesion, adaptability and communication. The items were developed to address these three dimensions. However, Fischer and Corcoran (2007) suggest that further research is needed before the FACES-III is seen to be a reliably measure as the alpha levels are below .7.

Qualitative evaluations

The FACES-III can be used with both families and couples by changing the wording to suit the need. On inspection of the items, this change can make them unsuitable for use with couples. For example the item: "When our family/ when we get(s) together for activities, everyone is present" is not appropriate for use with couples, as only two people would be present. The items also seem to be very general, which could result in different interpretations by participants.

Overall, there is a lack of evidence about the reliability and validity of the FACES-III when used in dementia care, and there are questions about its reliability and validity generally.

Dyadic Adjustment Scale (DAS)

Wright (1991) used the DAS (Spanier, 1976; Spanier & Thompson, 1982) to understand spouses' perceptions of their marital relationship when a diagnosis of dementia is made, employing the scale with couples in which one had dementia and healthy control couples. She asked both spouses in each couple to complete the DAS.

Description of measure

The DAS is a 32 item self report measure consisting of four factors: consensus, satisfaction, cohesion and affection. The consensus dyad refers to the agreement that a couple has over household tasks and has 13 items. The satisfaction dyad refers to the degree to which the couple are satisfied with their relationship and has ten items. The cohesion dyad purports to measure the amount of engagement experienced by the couple and has five items. Finally, the affection dyad, which refers to the sexuality and expressed affection in the relationship, has four items. The DAS uses a mixture of five and seven point Likert scales.

The DAS has been reported to be easily scored (Graham et al., 2006) and can be used to compare each of the spouse's views on his/her relationship. Spainer (1976) reports that for clinical and research purposes, individual factors can be considered or the DAS can be used to yield a total score. The total scores have cut off points, with below 92 being indicative of distress and above 107 suggestive of adjustment in the relationship, though no explanation is given for these (Spainer, 1989).

The DAS is a widely used tool both in research and in the assessment of clinical work, for example in marital therapy (Prouty, Markowski & Barnes, 2000). As well as measuring the spousal relationship in dementia care, the DAS has also been used to measure the effects of caring for a partner with arthritis and other clinical conditions (Walsh, Blanchard, Kremer & Blanchard (1991).

Quantitative evaluations

In the original standardisation of the DAS (Spanier, 1976), the sample used was 218 married couples and 94 recently divorced couples. All of the participants came from Pennsylvania and were white and working or middle class. This could restrict the use of the measure with couples from a different ethnic group, age, class or culture. However, Graham et al. (2006) conducted a meta-analysis with 403 papers that had used the DAS and reported that the DAS was not influenced by marital status, ethnicity, sexual orientation or gender.

In the initial development of the DAS, Spainer (1976) reported good reliability with an overall Cronbach's alpha of .96. The individual dyads also had good internal consistency (consensus $\alpha = .90$; satisfaction $\alpha = .94$; cohesion $\alpha = .86$; affection $\alpha = .73$). No re-test procedure has been carried out, thus is it difficult to know if the DAS is stable over time.

Spainer (1976) reported that the DAS has good content validity, concurrent validity and divergent validity. Content validity was assessed by having three external judges evaluate the items in the questionnaire as to whether they were appropriately worded and aimed to measure relationship adjustment. However, the development of the items was not generated from a particular theory but taken from existing relationship measures. Concurrent validity was verified by measuring the DAS against the Locke-Wallace Marital Adjustment Scale (1959), which was perceived by Spanier (1976) to be a reliable and valid measure. The correlation of these measures was r = .86, suggesting that the DAS has good concurrent validity. Divergent validity was assumed as the married and the divorced couples responded to the items in the DAS significantly differently from each other.

The sample used in the development of the DAS (Spainer, 1989) was not a representative sample of spousal carers. However, as noted it has been used very widely since including with those who care for partners with dementia (Wright, 1991). Wright (1991), however, does not report the existence of any psychometric data with her sample.

Qualitative evaluation

The value of using a total score is questionable. The factors have unequal weight and therefore contribute different amounts to the total. Thus two respondents may have equal scores but have very different feelings about their relationship. However, Graham et al. (2006) suggest that the use of the individual total dyad scores can be useful but must be combined with other evidence, such as an interview with the respondent. The DAS has a Likert response scale which varies from item to item. This may confuse respondents and may result in inaccurate responses being given. The terminology used in the DAS is

also dated, for example the use of “mate” to refer to a partner. The term “mate” may be interpreted as friend rather than a partner in today’s society.

In summary, the DAS has good psychometric properties (Graham et al., 2006). However, it has unequal weighting with regard to the four factors and the response scale is not consistent. Furthermore, the sample in the test construction did not include carers or people with dementia and unfortunately, Wright (1991) does not present α levels with the sample used in her research. Whether it is a reliable and valid measure when used in this context is therefore unclear.

Closeness and Conflict Scale

Schofield et al. (1998) used a battery of measures devised in their previous research (Schofield et al., 1997) to compare both the demands and the wellbeing of carers who cared for someone with dementia to carers of those with a physical impairment. The carers were physically ill in both cases. Schofield et al. (1997) designed several measures for the battery but one specifically measures closeness and conflict in relationships. For the purpose of this review, this will be referred to as the Closeness and Conflict Scale.

Description of measure

The Closeness and Conflict Scale (Schofield et al., 1997) has a total of six items, which are broken into two domains: ‘closeness’ and ‘conflict’. The closeness scale measures carers’ perceptions of compassion, love and closeness in their relationship. The conflict scale measures the amount of conflict, tension and resentment in the relationship. Respondents are asked to rate whether these six concepts occur less, the same, or more, following the diagnosis of dementia.

As well as the caring relationship in dementia, the Closeness and Conflict scale has also been used to measure the positive and negative changes in the relationship when

caring for individuals with other physical conditions (Schofield et al., 1998). Schofield et al. (1997b) have also used the Closeness and Conflict scale to assess the differential experiences of carer's relationships (e.g. spouse vs adult-child carer) when looking after those with long term illness and disability. This suggests that the scale can be used flexibly.

Quantitative evaluation

The items were selected from exploratory interviews conducted by Summers et al. (1989). The scale was reduced to six items from a possible ten in order to decrease the length of the instrument (Schofield et al., 1997). Schofield et al. (1997) selected these items as they had the highest item-total correlation in pilot analysis conducted by Herrman et al. (1994).

Schofield et al. (1997) suggest fair internal consistency of the measure on two different occasions: closeness $\alpha = .68$ (Herrman et al. 1993) and $\alpha = .73$ (Herrman et al. 1994). For the conflict domain, the internal consistency was $\alpha = .70$ (1993) and $\alpha = .75$ (1994). This suggests adequate reliability for the measure, although the closeness domain's Cronbach's alpha levels are somewhat borderline.

A factor analysis was also conducted with the data from Herrman et al. (1993, 1994). This confirmed that the six concepts from the two domains of closeness and conflict are separate dimensions and produced a two factor response, thus the Closeness and Conflict Scale has good construct validity.

The sample used in the development of the Closeness and Conflict scale (Schofield et al., 1997) consisted of 947 carers who were recruited via telephone calls from a household survey conducted over three months by the Australian Institute of Family Studies. During the telephone conversations, potential participants were asked if

they were the full time carers of an adult in the household who was elderly or had a long-term illness, disability or other problem. There were no exclusion criteria for gender or the relationship that the carer had with the person receiving their care. The descriptive statistics of the caregiver respondents are not reported in the paper (Schofield et al., 1997), thus it is not possible to draw conclusions regarding the appropriateness of this sample to spousal carers in dementia. The use of the measure in Schofield et al., (1998) suggests that the Closeness and Conflict Scale is suitable for use with spousal carers, as 25% of their participants were spousal carers of a partner with dementia. However, no psychometric data regarding reliability and validity are evident in Schofield et al.'s (1998) paper.

Qualitative evaluation

The items in the Closeness and Conflict Scale are short and would be easy to complete. However, there could be misunderstanding, as just one word is used for each item. Respondents could interpret these terms differently or in a narrow manner, as there is no definition of the words or indication of what they mean. For example, 'conflict' may be interpreted as a verbal argument or physical aggression. The items may also result in respondents answering in a socially desirable manner, as admitting to having more resentment or conflict in the relationship could be embarrassing or seen as unacceptable, thus preventing respondents from reporting honestly.

Overall, the Closeness and Conflict Scale has been successfully used with spousal carers of people with dementia and adequate reliability has been shown on two occasions (Herrman et al. 1993, 1994). However, more research is needed to gather data and evidence for validity for use with spousal carers.

Quality of Prior Relationship (QPR)

Kramer (1993) aimed to explore the effect that marital history and quality of the relationship before the onset on dementia had on outcomes for wives caring for their spouses. Kramer (1993) used the QPR (Williamson & Schulz, 1990) which is an adapted version of the Family Assessment Measure (FAM) initially designed by Skinner et al. (1983) and which is designed to assess the relationship prior to illness. The QPR to date has not been used with any other population.

Description of measure

The QPR (Williamson & Schulz, 1990) has three subscales with a total of 14 items that were selected from the original FAM for their ability to measure the quality of a prior relationship in terms of communication, affected expression and involvement. Items for communication are: "I knew what this person meant when he or she said something" and "This person took what I said the wrong way". Items for affected expression include: "When I was upset this person knew why" and "When this person got angry with me, he or she stayed upset with me for days". Finally, involvement consists of items such as: "This person and I weren't close to each other" and "When I was upset I knew that this person really cared". These six items are the only items presented for the QPR (Williamson & Schulz, 1990).

The items were responded to using a four point Likert scale, 1 = strongly disagree; 4 = strongly agree. The totals were added together, with scores ranging from 14- 56, following reversal of the positive items. The lower the total score, the closer the prior relationship.

Quantitative evaluation

The total sample used by Williamson and Schulz (1990) was N = 174, of whom 71 were spousal full time carers; the remainder being made up of adult family carers. The participants were recruited via diagnostic centers in Pittsburgh, USA. Kramer's (1993) sample consisted of 72 wives who cared for their spouses on a full time basis. The wives had a mean age of 70 years and were recruited through 12 different memory clinics in Washington State, USA. Both of the samples appear to be representative of the carer population.

Satisfactory levels of reliability data pertaining to the internal consistency of the QPR were reported by Williamson and Schulz (1990) as $\alpha = .87$. Kramer (1993) also reported good internal consistency with her sample: $\alpha = .80$. There is however, no data suggesting test re-test reliability, thus the measure may be vulnerable to environmental influences or fluctuation in a respondent's mood.

Williamson and Schulz (1990) do not offer any information regarding the validity of their new measure nor indicate why it was developed, suggesting a lack of incremental validity. However, the measure does appear to measure what it is intended to measure, suggesting good face validity.

Qualitative evaluation

Only six of the possible 14 items were available from the information presented in Williamson and Schulz (1990) paper. From the six items reported by Williamson and Schulz (1990), some of the items could be evaluated as having strong emotional content. For example, asking the respondent to agree or disagree with the statement: "When I was upset I knew that this person really cared" could be upsetting, as the past tense wording suggests that the person with dementia is no longer living. Furthermore, it could be

argued that the items are very leading and make judgments. In summary, the QPR has good internal consistency but is lacking in validity data.

Discussion

The results of the current review suggest that there is little information given in the literature regarding the psychometric properties of the measures used to evaluate the marital relationship in dementia care. There is also little evidence regarding the construction of the reported measures and there appears to be no consistency in their development or in the reporting of their reliability and validity data.

From the information presented in the papers reviewed, it appears that some of the measures have no reliability data concerning their use with spousal carers in dementia so it is possible that using them with spousal carers may not produce reliable data. Examples are the BRSS (Burns & Sayers); Mutuality Scale (Archbold et al., 1990); University of Southern California Longitudinal Study of Three-Generation Families Measure of Positive Affect (Mangen, Bengtson & Landry, 1988); FACES-III (Olson, 1986) and DAS (Wright, 1991). Of the nine measures reviewed, none of them report test-retest-reliability, and so it is not possible to conclude that the measures are stable over time and they may be affected by mood or other transient factors.

Of the nine measures reviewed it is noted that four have also been used with samples of spouses caring for older people with a range of physical conditions and illnesses (FACES, DAS, Mutuality scale and Closenss and Conflict Scale). Whilst not directly comparable, these caregivers are likely to have something in common with dementia caregivers. Thus where their use in these other contexts demonstrates validity and reliability this implies the scale is fairly likely to be usable with spouse carers for people with dementia.

As a whole, the papers report little validity data about the use of the measures with spousal carers in dementia. With regard to construct validity, there is a lack of any theoretical background to most of the measures or even an account of why particular aspects of the relationship were assessed. There is also a lack of any user involvement or consultation with representatives from the population for which the measures were intended. The samples used in the development of the measures are relatively small, for example Morris, Morris and Britton (1988, n = 20) and Eloniemi-Sulkava et al. (2002, n = 42), and such samples may not be representative of the intended wider population. These two papers however were designed to answer a specific research question and were not designed for replication. Nevertheless, the lack of information presented about the construction and the validation of the measure used suggests that the data produced by the measure may not be sound, thus it could discredit the research findings of these papers.

From the results of this evaluation it has also been noticed that cultural and social norms, attitudes and beliefs are not taken into account when describing some of the measures, which have been developed with restricted groups. This may potentially affect the generalisability of the measure to other populations as they have been initially developed in a particular social context. Although most of the measures are reasonably short, there is little consideration of user acceptability.

With regard to the initial development of the measures and their application to research, only two ask the person with dementia about their views of the quality of their relationship (Wright, 1991; Reilly, Relkin & Zbrozeh, 2006). Understandably, the level of dementia could affect the response but the majority of those with early dementia would be able to respond to interview questions.

As can be seen in Table 1.2 there are different concepts being included in these measures of spousal relationships. Overall there are 25 different concepts being measured, with the greatest replication for communication and perceived closeness. The amount of variance in the concepts appears to be due to some of the measures taking quite a narrow view of relationship quality (e.g. communication only) whereas others have taken a rather broad view. This variation could be a result of little agreement about which domains are needed to assess relationships. As mentioned above, the majority of the measures presented in this review are not based on any theoretical foundations. A clear theoretical underpinning for what constitutes relationship continuity may help to address this issue.

This review calls for standardised guidelines in scale development as well as consistency from researchers in reporting data necessary for judgements to be made regarding a measure's appropriateness for use with spousal carers. A good example of a well developed measure is the DAS (Spainer, 1976). Information was provided about item development and data were given relating to reliability and validity. The DAS has been widely used in research measuring relationship quality but there is little evidence about its use in dementia. However, further research could address this.

In summary to date there are limited measures of relationships for use in understanding the impact of dementia on the spousal relationship.

References

Archbold, P., Stewart, B.J., Greenlick, M.R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research and Nursing Health, 13*, 375-384.

Barker, C., Pistrang, N., & Elliott, R. (2002). *Research methods in clinical psychology: An introduction for students and practitioners.* London: John Wiley.

BrintzenhofeSzoc, K.M., Smith, E.D., & Zabora, J.R. (1999). Screening to predict complicated grief in spouse of cancer patients. *Cancer Practice, 7*(5), 233-239.

Burns, D.D., & Sayers, S. (1988). Cognitive *and affective components of martial satisfaction: Development and validation of a brief relationship scale*. Unpublished manuscript.

Capezuti, E., Zwicker,D., Mezey, M., & Fulmer, T. (2008). *Evidence-based geriatric nursing protocols: Best practice*. New York: Springer Publications.

Cronbach, L. J., & Shavelson, R. J. (2004). My current thoughts on coefficient alpha and successor procedures. *Educational and Psychological Measurement, 64,* 391-418.

Deeken, J. F., Taylor, K. L., Mangan, P., Yabroff, K. R., & Ingham, J. M. (2003). Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management, 26*(4), 922-953.

DeVellis, R.F. (2003). *Scale development: Theory and application* (2nd edition). Thousand Oaks, CA: Sage.

De Vugt, M.E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I,. Jellemer, J., & Verhey, R.J. (2003). Behavioral disturbances in dementia patients and quality of the martial relationship. *International Journal of Geriatric Psychiatry, 18*, 149-154.

Eldredge, D., Nail, L.M., Mazlaz, L.K., Hansen, D.E., & Archbold, P.F. (2006). Explaining family caregiver role strain following autologous blood and marrow transplantation. *Journal of Psychosocial Oncology, 24*(3), 53-74.

Eloniemi-Sulkava, U., Notkola, I., Hämäläinen, K., Rahkonen, T., Viramo, P., Hentinen, M., Kivelä., & Sulkava, R. (2002). Spouse caregivers' perceptions of influence of dementia on marriage. *International Psychogeriatrics*, *14*(1), 47-58.

Fischer, J., & Corcoran, K. (2007). *Measures for clinical practice and research*: *couples, families, and children*. New York: Oxford University Press.

Gallagher-Thompson, D., Dal Canto, P., Jacob, T., & Thomson, L., (2001). A comparison of marital interactions patterns between couples in which the husband does or does not have Alzheimer 's disease. *Journal of Gerontology*, 56B(3), S140-S150.

Garand, L., Dew, M.A., Urda, B., Hagerty-Lingler, J., DeKosky, S., & Reynolds, C. (2007). Marital quality in the context of mild cognitive impairment. *Western Journal of Nursing Research, 29*(8), 976-992.

Graham, J., Liv, Y.J., & Jeziorski, J.L. (2006). The dyadic adjustment scale: A reliability generalization meta-analysis. *Journal of Marriage and Family, 68*(3), 701-717.

Goddard, R.D III., & Villanova, P. (2006). Designing surveys and questionnaires for research. In T.L. Leong & J. Austin. (eds). *The psychology research handbook.* (pp.58-97). Portland: Sage Publications.

Gronewold, K. , DeGreeff, B. L. and Semlak, J. L. , 2008-11-20 "Satisfied Siblings?: Considering Sex Composition of Dyads, Age Differences, and Attachment as Predictors of Relational Satisfaction" Paper presented at the annual meeting of the NCA 94th Annual Convention, TBA, San Diego, CA Online <PDF>. 2010-06-06 from http://www.allacademic.com/meta/p258420_index.html

Hellström, I., Nolan, M., & Lundh, U. (2007). 'Sustaining couplehood'. *Dementia, 6,* 383-409.

Herrman, H., Singh, B., Schofield, H., Eastwood, R., Burgess, P., Lewis, V., & Scotton, R. (1993). The health and wellbeing of informal caregivers: a review and study problem. *Australian Journal of Public Health,* 17, 261-266.

Herrman, H., Schofield, H., Murphy, B. & Singh, B. (1994). The experiences and quality of life of informal caregivers. In J. Orley & W. Kuyken. (eds). *Quality of Life Assessment: International Perspectives.*(pp 131-150). Berlin: Springer-Verlag.

Kline, P. (2000*). A Psychometrics Primer.* London: Free Association Books.

Knop, D.S., Bergman-Evans, B., & McCabe, B.W. (1998). In sickness and in health: An exploration of the perceived quality of the martial relationship coping and depression in caregivers of spouse with Alzheimers disease. *Journal of Psychosocial Nursing, 36*, 16-21.

Kneeshaw, M, F., Considine, R.M., & Jennings, J. (1999). Mutuality and preparedness of family caregivers for elderly women after bypass surgery. *Applied Nursing Research, 12*(3), 128-135.

Kramer, B.J. (1993). Martial history and the prior relationship as predictors of positive and negative outcomes among wife caregivers. *Family Relations, 42*, 367-375.

Leong, F, T., & Austin, J. (2006). *The Psychological Research Handbook.* (eds.). Portland: Sage Publications.

Locke, H, J. & Wallace, K.M. (1959). Short marital adjustment and prediction test: their reliability and validity." *Marriage and Family Living, 21*, 251-255 .

Mangen, D.J, Bengtson, V.L. & Landry, P.H. (eds.) (1988). *Measurement of intergenerational relations.* Beverly Hills: Sage.

Murray, J., Schneider, J., Banerjee, S. & Mann, A. (1991). EUROCARE a cross national study of co-resident spouse carers for people with Alzheimers dementia II: a qualitative analysis of the experience of caregiving. *International Journal of Geriator Psychiatry, 17,* 1128-1132.

Morris, R.G., Morris, L.W., & Britton, P.G. (1988). Factors affecting the emotional well-being of the caregivers of dementia sufferers. *The British Journal of Psychiatry, 153*, 147-156.

Olson, D.H., Porter, J. & Lavee, Y. (1985). Family adaptability and cohesion evaluation scale (FACESIII). In D.H. Olson. *Family inventories.* (eds.). St Paul: University of Minnesota Press.

Olson, D.H. (1986). Circumplex Model VII: Validation Studies and FACES-III. *Family Process, 25,* 337-351.

Pedhazur, E.J. & Schmelkin, L.P. (1991). *Measurement, design, and analysis: An integrated approach.* Hillsdale, NJ: Lawrence Erlbaum.

Prouty, A., Markowski, E.M., & Barnes, H.L. (2000). Using the DAS in marital therapy: An exploratory study. *The Family Journal, 8*(3), 250-257.

Quinn, C., Clare, L., & Woods, B. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging and Mental Health. 13*(2), 143-154.

Rankin, E.D., Haut, M.W., & Keefover, R.W. (1992). Clinical assessment of family caregivers in dementia. *The Gerontologist, 32*(3), 813-821.

Reilly, M., Norman, R., & Zbrozek, A.S. (2006). Development and testing of a new outcome measure of relationship between patients with Alzheimer's disease and their Partners. *American Journal of Alzheimer's Disease & Other Dementias, 21*(4), 249-257.

Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology, 38*, 344- 348.

Roy, R., & Thomas, M.R. (1989). Nature of martial relations among chronic pain patients. *Contemporary Family Therapy, 11*(4), 277-285.

Schofield, H.L., Murphy, B., Herrman, H.E., Bloch, S., & Singh, B. (1997). Family caregiving: Measurement of emotional well-being and various aspects of the caregiving role. *Psychological Medicine, 27*, 647-657.

Schofield, H.L., Murphy, B., Nankervis, J., Singh, B., Herrman, H.E., & Bloch, S. (1997b). Family Carers: Women and men, adult offspring, parents and partners. *Journal of Family Studies, 3*(2), 149-168.

Schofield, H.L., Murphy, B., Herrman, H.E., Bloch, S., & Singh, B. (1998). Carers of people aged over 50 with physical impairment, memory loss and dementia: a comparative study. *Aging and Society, 18*, 355-369.

Skinner, H.A., Steinhauer, P.D. & Santa-Barbara, J. (1983). The family assessment measure. *Canadian Journal of Community Mental Health, 2*, 91-105.

Steadman, P., Tremont, G., & Duncan-Davis. (2007). Premorbid Relationship Satisfaction and Caregiver Burden in Dementia Caregivers. *Journal of Geriatric Psychiatry and Neurology, 20*(2), 115-119.

Streiner, D.L. & Norman, G.R. (2003). *Health measurement scales: A practical guide to their development and use.* (Third Ed). Oxford: Oxford University Press.

Spanier, G. (1976). Measuring Dyadic Adjustment: New Scales for Assessing the Quality of Marriage and Similar Dyads. *Journal of Marriage and the Family, February,* 15-28.

Spanier, G., & Thompson, L. (1982). A confirmatory analysis of the Dyadic Adjustment Scale. *Journal of Marriage and the Family, August,* 731-738.

Summers, J.A., Behr, S.K., & Turnbull, A.P. (1989). Positive adaptation and coping strengths of families who have children with disabilities. In G.H.S Singer & L.K. Irvin (eds.), *Support for caregiving families* (pp. 27-40). Maryland: Paul H. Brookes Publishing Co.

Thorndike, R.M. (1997). *Measurement and evaluation in psychology and education* (6th ed.). Upper Saddle River, NJ: Prentice Hall.

Walsh, J., Blanchard, E., Kremer, J., & Blanchard, C. (1999). The psychological effects of rheumatoid arthritis on the patient and the well partner. *Behaviour Research and Therapy, 37*(3), 259-271.

Waring, E. & Patton, D. (1984). Marital intimacy and depression. *British Journal of Psychiatry, 145,* 641-644.

White, C., Poissant, L., Cate-LeBlanc, G., & Wood-Dauphinee, S. (2006). Long-term caregiving after Stroke. The impact on caregiver's quality of life. *Journal of Neuroscience Nursing, 38*(5), 354-360.

Williamson, G.M., & Schulz, R. (1990). Relationship orientation, quality of prior relationship, and distress among caregivers of Alzheimer's patients. *Psychology and Aging, 3*(4), 502-509.

Wright, L. K. (1991). The impact of Alzheimers disease on the marital relationship. *The Gerontologist, 31*(2), 224-237.

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of impaired elderly: correlates of feelings of burden. *Gerontologist. 6,* 649-655.

Paper 2

Construction and Initial Validation of a Measure of Relationship Continuity when Caring for a Spouse with Dementia.

Gemma Fisher 2010

Abstract

This paper describes the construction and validation of a new measure, the *Birmingham Relationship Continuity Measure* (BRCM). The BRCM is a 26 item instrument designed to measure continuity of spousal relationships, as perceived by the caregiving spouse, where one of the couple cares for the other, due to a diagnosis of dementia.

The measure is based on the findings of Walters (2008) who suggested six domains that are important when considering continuity and discontinuity in a spousal caring relationship. These were: changes in relationship; changes to the person; changes in feelings; sense of loss; sharing and togetherness; and the expressions of affection and attachment.

The initial version of the measure had 47 items which were approved by a focus group made up of four husbands currently caring for their wives. This version was then given to a sample of carers (N = 51). Items were assessed in terms of their inter-item consistency, discriminative power and the extent to which they represented the six domains. This resulted in a reduction to 26 items, with the overall measure showing good internal consistency (Cronbach's alpha = 0.94).

The revised version was given to a second sample (N = 21), along with two other measures (the Closeness and Conflict Scale, Schofield et al., 1998; and the Marwit-Meuser Caregiver Grief Inventory, Marwit & Meuser, 2002) to assess concurrent validity. Good internal consistency was again achieved (Cronbach's α = .94). Fourteen participants of the final sample agreed to complete the new measure a second time, and good test re-test reliability was achieved (intra-class correlation coefficient = .92). Evidence of concurrent validity was also obtained: Moderate correlations were observed

between the BCRM and the *heartfelt sadness and longing* subscale of the Marwit-Meuser Caregiver Grief Inventory (r = -.542) and between the BCRM and the Schofield Closeness and Conflict scale (r = .428).

Introduction

Carers are defined in the Government's White Paper (*Carers at the Heart of 21st Century Families and Community*) as: "Spending a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems" (Department of Health, 2008 p.11).

The UK 2001 Census indicated that there were six million carers in the adult population and that 1.5 million of these were over 50 (Office for National Statistics, 2001). Eighteen percent of these were caring for a spouse. Lewis (1998) suggested that the responsibility for community-based care of older adults is usually given to the spouse. Murray (1995) suggests that older adult spouse carers experience feelings of burden and increased rates of depression; and spousal carers are at higher risk of developing depression than age-related peers who do not perform the caring role (Murray & Livingston, 1998). The responsibility of being a full-time carer for a spouse can be difficult and research that furthers our understanding of caregiving is therefore justified.

Some findings indicate that the caring role can be positive if a carer finds meaning and reward in looking after his or her partner (Menenko, 1998). Other research suggests that the role can be challenging, especially when a carer views the change in their relationship as negative (Van Den Wijgaart, Vernoonij-Dassen, & Felling, 2007). Feelings of burden are common for carers, as the role of caring is both physically and psychologically demanding (Vitaliano, Zhang, & Scanlan, 2003). Schulz et al. (2002) reported that many carers feel trapped by their caring roles. There can also be increased feelings of guilt, especially when the carers have to relinquish their caring roles to professional carers (Kaplan, 2001). Ott, Sanders and Kelber (2007) compared spousal

carers with adult-child carers of people with dementia using a caregiver grief model and found that spouses experienced more personal sacrifice and burden than adult –child caregivers. In contrast, adult-child caregivers experienced more personal growth than spouses.

In recent years, there has been an increasing interest in how dementia impacts on the relationship between the person with dementia and their partner. When one person in a relationship develops dementia, there are inevitable changes in the way that the couple interact. Many different dimensions of the marital relationship change, including approaches to household tasks, companionship, affection and intimacy (Wright, 1993; Kaplan, 2001), reflecting the dependency of the person with dementia (Garand et al., 2007). Some recent research has focused on how these changes affect the kind of relationship the couple have.

Kaplan (2001) studied the effect that placing a partner into full-time care had on the carer's perception of his or her relationship. He did this by completing 68 qualitative interviews with 42 woman and 26 men whose partner had been institutionalised. The themes generated from the interviews highlighted a "couplehood typology" as a way of identifying how carers perceived their marital relationship. The typology is seen as a continuum from carers still seeing their relationship as a strong "we" to others moving towards a strong sense of "I".

The idea of disintegration in the sense of couplehood in dementia care is not unique to Kaplan (2001). Chesla, Martusan and Muwases (1994) interviewed 15 spouse carers and 15 child carers and suggested three types of relationships: "continuous", where the relationship is seen as a continuation of the previous relationship; "continuous but transformed", where the relationship is viewed as still there but involves less reciprocity;

and “radically discontinuous”, where there is emotional distance between the two people in the relationship, although the carer still gives a good level of care to the spouse.

Murray and Livingston (1998) interviewed 307 carers whose spouse had a psychiatric condition (including dementia) and the themes similarly suggested that the carer may no longer see their partner as their partner but more of an object or shell of the former person. The authors also found that if the carers still perceived “continuity” in the relationship, they were more likely to tolerate difficult behaviour.

Hellstrom, Nolan and Lundh (2007) interviewed 20 couples over five years and suggested that couples go through three phases after receiving a diagnosis of dementia in order to maintain a positive relationship: “sustaining couplehood”, “maintaining involvement” and “moving on”. Passing thorough these phases allows the relationship to flourish by developing “nurturative relational context”. Hellstrom et al. also highlighted that the spouse suffering with dementia has an active role in the maintenance of the relationship.

Research conducted by Walters (2008) explored six female carers' perceptions of their relationship with their husbands who had a diagnosis of dementia. The findings of the qualitative study suggested that changes in the carers' experience of closeness and distance in the relationship varied across individuals. Some experienced discontinuity and distance in their relationships but for others the experience was regarded as a continuation of their longstanding relationship. Discontinuity in the relationship seemed to be associated with negative emotions of caring, such as guilt and feelings of entrapment.

There are, then, several papers in the research literature suggesting that carers differ in terms of relationship discontinuity and some have suggested that discontinuity is associated with more negative emotional reactions to the caring role. These ideas have

been based on qualitative studies and it would be useful to have additional quantitative support for them. A first step towards this would be to develop a standardised instrument to measure the relationship. The aim of this study, therefore, was to develop a questionnaire to measure the phenomenon of continuity in the spousal relationship that is both reliable and valid and can discriminate between carers who have continuity in their relationship and carers who do not. This could aid clinicians in identifying and supporting spouse carers of dementia, as well as providing a measure for the quantitative investigation of relationship continuity. The measure was developed specifically for use with spouse carers.

Method and Results

Procedure

The questionnaire was developed using the methodology, outlined by Kline (2000). The procedure and results of each of the five phases of development are outlined below.

PHASE 1 - Construction of initial questionnaire

Initially 47 items were developed which had relevance to the phenomenon to be measured. Items were generated from transcripts of previous research conducted by Walters (2008) who used qualitative methods to investigate the carer's perspective of how the couple interacted with one other, specifically communication, dependency and shared activities both before and after the onset of dementia. Walters suggested six domains that contribute to continuity or discontinuity in the relationship and these can be seen in figure 2.1.

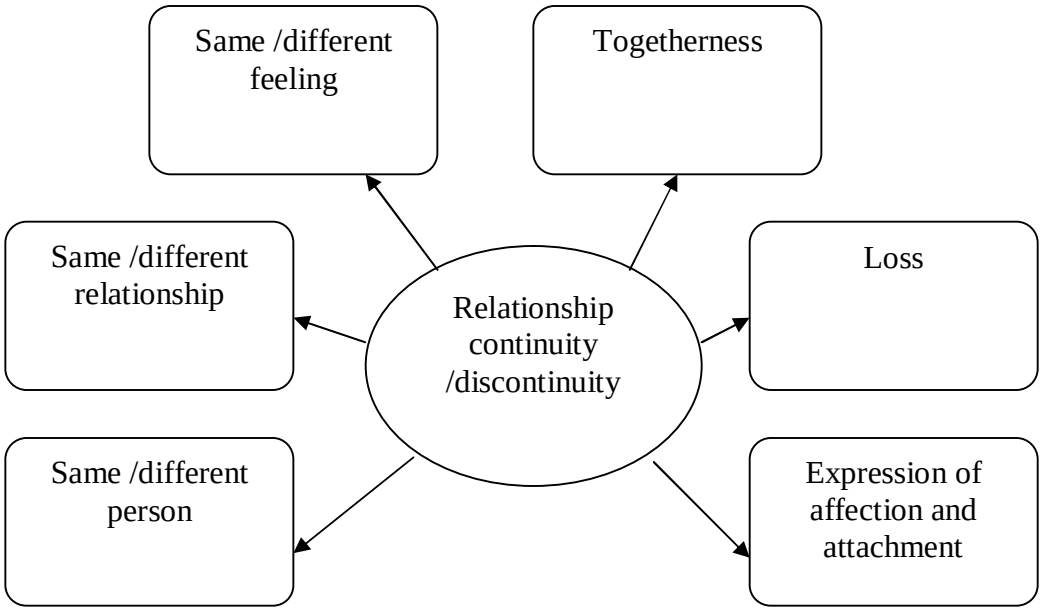

Figure 2.1. Illustrating the six domains found by Walters (2008), used in item development.

The 47 items were based on the six dimensions and are presented in Table 2.2. Items were both negatively and positively word as suggested by Kline (2000).

Same/different relationship: Items in this domain represent the most direct evaluation of whether the carer perceives that there is relationship continuity. They relate to the question of whether the carer feels that the essence of the relationship has changed in some fundamental way. There were a total of six items in this domain. An example is *'It doesn't feel like a partnership any more'*

Same/different person: Items in this domain relate to the question of whether the carer feels that their partner has changed in some fundamental way, for example that the person with dementia has changed who they are as a person and that this has altered their personal identity. There were a total of nine items in this domain. They were included on the grounds that if a carer perceives that their partner is a different person, then they are not likely to perceive continuity in the relationship, since those fundamental qualities that

attracted and bound them together will have changed. An example item is *'Sometimes I feel it's like living with a stranger'*.

Loss: In this domain items relate to whether the carer feels a sense of loss in relation to how their partner or their relationship used to be. There was a total of six items in this domain. They were included as a sense of loss is presumably an indication that the current person or relationship is perceived in a very different way to the previous person or relationship which is now perceived as lost, suggesting discontinuity. An example item for the loss domain is *'I miss having someone to share my life with'*

Same/different feelings: In this domain items relate to whether the carer feels the essential bond that couples feel for each other is still there. There were a total of nine items in this domain. The rationale for their inclusion was that bonds are central to the relationship, and that changes to these bonds will create a very different relationship. An example item is *'The bond between us is as strong as ever'*

Sharing/Togetherness: This domain and items within it relate to whether the couple still share and do things together as a couple. The rationale for their inclusion is that no longer acting together as a couple would remove the sharing and togetherness that cements the bond and defines the relationship, again creating a very different relationship. There were a total of nine items in this domain an example item is *'We face our problems as a couple, working together'*.

Expression of affection and attachment: This domain contains items that relate to whether the carer expresses affection, and vice-versa. As with the sharing and togetherness domain, mutual affection and attachment cements the relationship, hence carers who feel affection may feel more continuity in their relationship. There were a

total of eight initial items in this domain. An example is *'We still share a kiss and cuddle together'*

PHASE 2 - Focus group

Following the development of the 47 item questionnaire, it was taken to a focus group for user feedback regarding readability, user acceptability and the most appropriate response format. Twenty-one letters were sent to spouse carers who were members of a carers' support group in the West Midlands, inviting them to take part in the focus group. Six carers replied, however two failed to attend leaving four participants (for a version of the participant's information pack, see appendix C). The participants were fully informed about the research and signed a consent form. They were four husbands with a mean age of 75 (SD 7.0). Three of the wives they cared for had a diagnosis of probable Alzheimer's disease and one wife had a diagnosis of vascular dementia. The average length of marriage was 41 years (*SD* 21) and the time since the partner's diagnosis of dementia was 2.6 years (*SD* 1.25).

The schedule for the focus group can be found in Appendix B. Firstly, participants were asked to choose a preferred response format from two alternatives: yes-no or a five point Likert response. Preference for the use of the five point Likert scale was unanimous. The focus group reported that they favored the Likert response as it had a neutral 'neither' option and being able to agree or disagree a little or a lot also felt more comfortable to the focus group.

Participants were then asked to complete the questionnaire and make any notes of thoughts they had about the measure as they did so. The participants were asked to notice in particular, if any of the items were distressing, confusing or embarrassing to them. Once all the members had completed the questionnaire a discussion was held about the

measure. The feedback resulted in some small changes being made to the instructions for the measure and wording of two of the items. A major change to the measure suggested by the focus group was to have a male and female version as they thought that this would be easier to follow and would increase user acceptability. The Flesch Reading Ease (Flesch, 1948) analysis of the 47 items revealed a value of 80.7, indicating that the questionnaire would be easily readable by an average 12-year-old or any persons with little formal education.

PHASE 3- Initial Sample

The 47 item measure was piloted with an opportunistic sample of spouse carers recruited via the Alzheimer's Society, West Midlands. Overall, 140 information packs containing a covering letter, information sheet, consent form, demographic questionnaire and the relationship continuity measure were sent out by the Alzheimer's Society to all spouse carers they were aware of who attended Alzheimer's Society events (the information packs sent to participants can be seen in Appendix C). A background demographic questionnaire (see Appendix C) was included for completion in order to provide a good description of the sample. The questions were broken into two sections to ascertain the level of challenging behaviour and care needs of the person being looked after (e.g. *Does your partner sometimes become distressed and agitated?)* and the degree of support received (e.g. '*Do carers come in on a regular basis to help you in looking after your partner?*'). The information given in response to these questions was used to explore whether relationship continuity was related to challenging behaviour or the support needs of the carer (see Table 2.1).

Potential participants were asked to read the information sent to them and, if they would like to take part, to return the questionnaires and consent form via the stamped

addressed envelope. Thirty-one participants were recruited in this manner. Another 50 information packs were given out to potential participants at the Alzheimer's Society organized coffee mornings. Participants were given the choice of completing the questionnaire and returning it at the coffee morning or taking the information pack home and returning it in the pre-paid and addressed envelope. A total of 20 participants were recruited in this manner.

The total sample consisted of 51 English speaking spouse carers. There was an overall response rate of 26%. Thirty-one of the participants received respite care for their spouse, but all still lived with their spouse. There were 23 wives and 28 husbands. The mean age was 73 years (SD 7.6). The average length of the marriage was 47.8 years (SD 11.7) and participants in this sample reported caring for their spouse for an average of 3.87 years (SD 3.0). With regard to types of dementia: 27 had Alzheimer's dementia; 14 had vascular dementia; 3 reported mixed dementia; 2 had frontal temporal dementia and 5 left this question blank. Details of the sample are presented in Table 2.1.

Table 2.1 Demographic characteristics of participants.

	Pilot Sample N = 51	**Final Sample N = 21**
Age	*M* = 73 years *SD* = 7.6	*M* = 72 years *SD* = 7.5
Gender		
Male	28	8
Female	23	13
Ethnicity		
White British	*N* = 51	*N* = 21
Religion		
Christian	*N* = 42	*N* = 20
No religion	*N* = 9	*N*= 1
Length of relationship	M = 47.8 years , SD =11.7	M = 42, SD 14.7
Type of dementia		
Alzheimers	*N = 27*	*N = 16*
Vascular	*N= 14*	*N = 3*
Mixed	*N= 3*	
Lewy Bodies	*N = 1*	
Frontal Temporal	*N= 2*	*N = 2*
Missing	*N = 4*	
Duration of dementia	*M = 3.8 years SD = 3*	*M = 3 years SD = 1.5*
SUPPORT		
Length of caring	*M = 5.1 years SD = 7.8*	*M = 6 years SD = 12*
Informal caring support		
Yes	31	11
No	20	10
Formal caring support		
Yes	14	6
No	37	15
Respite		
Yes	20	3
No	31	18
Day care		
Yes	24	4
No	27	17
Taking time for yourself		
Yes	39	13
No	12	8

CHALLENGING BEHAVIOURS	Pilot Sample N = 51	Final Sample N = 21
Leaving your partner alone		
Yes	36	13
No	15	7
Disturbed sleep		
Yes	24	13
No	27	7
Partner's agitation		
Yes	36	16
No	15	5
Repeated questioning		
Yes	43	21
No	8	
Physical aggression		
Yes	13	4
No	38	17
Draws public attention		
Yes	21	7
No	30	14
Difficulty persuading your partner to do things		
Yes	37	8
No	14	13
Assist your partner to dress		
Yes	36	8
No	15	13
Assist your partner to eat		
Yes	15	7
No	36	14
Assist your partner to toilet		
Yes	17	6
No	34	15

PHASE 4- Analysis of initial data

The 'item analysis' approach to test construction (Kline, 2000) was used to analyse the results of the third phase. This analysis aimed to remove items with lower discriminative power and those with low item-total correlations, and also to ensure that the different domains were adequately represented. The analysis involved the following steps:

- Item 47 *'It upsets me to think about what he used to be like"* was removed as it had been missed out by 23.5% (N =12) of the participants.
- Ten items had not been completed by one or two participants. The missing value was substituted with the mean of that item across participants who had completed the item.
- Items were then removed if they had low discriminative power, i.e. if there were 10 or fewer participants in the 'minority' on the item (i.e. if there were 10 or fewer who answered either 'agree a lot' or 'agree a little' [or 'disagree a lot' or 'disagree a little']). This resulted in 17 items being removed. Examples of the items that were removed due to poor discriminative power are: *'I often think about the difference between our life now and the way it used to be'* (item 20) and '*I enjoy thinking about the good times we used to have'* (item 38).
- Once these items had been removed, an analysis of the internal consistency was conducted to inspect the item-total correlations of the remaining items. Two items had item-total correlations below 0.3 (which is considered the benchmark for inclusion – Kline, 2000) and these were accordingly removed.

- The remaining items were then considered in terms of their content validity – i.e. whether they were representative of the six domains that were involved in the initial conceptualization of relationship continuity. Each domain was represented by at least three items, with the exception of the *loss* domain which was represented by no items. The six *loss* items were re-entered into a reliability analysis alongside the remaining items, and their item-total correlations calculated. These were reconsidered alongside the data about the ability of each item to discriminate the sample. Two items had good item-total correlations (above 0.6) and these were re-included in the questionnaire. To ensure representation of the domain by at least three items, a third loss item was chosen that represented the best combination of item-total correlation and discriminative power.
- A further three items were removed from the expressions of affection and attachment domain as, on reflection, the items asked the carers to respond about the person with dementia rather than about the perceived continuity of the relationship, an example of one of these items being, *'I don't feel he appreciates what I do for him'*.

A reliability analysis was completed on the 26 items still retained in the questionnaire and this resulted in the overall Cronbach's alpha level of $\alpha = 0.94$, with item-total correlations ranging from .28 to .79 (see Table 2.2). Examination of the total score for the 26 items also showed a distribution that was reasonably close to the normal distribution (see appendix F). Reliability analysis was also separately conducted for each of the six domains. This showed Cronbach's alpha level ranging from 0.52 to 0.89 and item total correlations ranging from .01 to .93 (see Table 2.3).

Table 2.2. The 47 item questionnaire with items deleted highlighted and total item total correlation.

Same/different relationship	**Reason for removal or Item Total**	**Same/different Person**	**Reason for removal or Item Total**
I feel like his carer now not his wife.	*.650*	He's the same man he ever was	LITC
Compared to how it was before the dementia, our relationship is now very different.	LD	He's a shadow of his former self.	*.557*
Our relationship had changed beyond recognition since the dementia started.	LD	I don't feel I really know him any more.	*.388*
Despite all the changes, our relationship has remained much the same as it was.	*.599*	Sometimes I feel it's like living with a stranger.	*.493*
Since the dementia started, we don't have the same sort of relationship any more.	LD	Despite all the changes, he's still his old self	*.535*
It doesn't feel like a partnership anymore.	*.583*	His old personality often comes through	LD
Loss		He still has many of the same qualities that first attracted me to him	*.604*
I feel I've been grieving for him.	*.282*	The dementia has changed his personality a lot.	LD
It upsets me to think about what he used to be like.	MD	Compared to how he used to be, he's a different person altogether now.	*.598*
I enjoy thinking about the good times we used to have.	LITC	**Same different feelings**	
I miss having someone to share my life with.	*.676*	I feel shut off from him.	*.559*
I often think about the differences between our life now and the way it used to be	LD	The bond between us isn't what it used to be.	*.665*
I feel like I've lost the person I used to know.	*.528*	It's like there's a barrier between us now.	*.743*

Sharing/togetherness		I don't feel about him the way I used to.	*.663*
I still try to involve him in important decisions.	LD	I feel close to him	LD
Sometimes I prefer to eat my meals without him.	LD	The bond between us is as strong as ever	*.668*
I don't feel I can share my worries and concerns with him.	LD	The dementia has brought us closer together emotionally.	*.732*
It feels lonely in this relationship.	LD	I love him as much as ever	LD
He's in a world of his own most of the time.	*.542*	I care for him, but I don't love him the way I used to.	*.655*
We face our problems as a couple, working together.	*.527*	**Expressions of affection & attachment**	
We still do things together that we both enjoy.	*.426*	It makes me feel uncomfortable if he is affectionate towards me.	*.533*
We can still have a laugh together.	LD	Sometimes I feel he invades my personal space.	*.789*
I only tell him what he needs to know.	*.337*	I don't like it if he comes too close to me.	*.590*
		We still have a kiss and a cuddle together.	LD
		I don't get much of a positive response from him any more	NRC
		I miss having someone to turn to when I need some comfort or support.	LD
		It feels like I put a lot into the relationship, but get little back.	NRC
		I don't feel he appreciates what I do for him.	NRC

***LD** – excluded because of low discrimination*
***LITC** – excluded because of low item-total correlation*
***MD** – excluded because of high amount of missing data*
***NRC** – excluded because it did not ask about relationship continuity*

Table 2.3. The final 26 item questionnaire: item-total correlations within each domain and overall internal consistency in each domain.

Domain	Item Total Correlation	Overall Cronbach Alpha
Same Different Relationship		.87
I feel like his carer now not his wife.	.62	
Despite all the changes, our relationship. has remained much the same as it was.	.71	
It doesn't feel like a partnership anymore.	.93	
Loss		.78
I feel I've been grieving for him.	.64	
I miss having someone to share my life with.	.52	
I feel like I've lost the person I used to know.	.82	
Same Different Person		.89
He's a shadow of his former self.	.58	
Despite all the changes, he's still his old self.	.85	
Sometimes I feel it's like living with a stranger.	.88	
I don't feel I really know him any more.	.64	
He still has many of the same qualities that first attracted me to him.	.53	
Compared to how he used to be, he's a different person altogether now.	.80	
Same Different Feeling		.80
I feel shut off from him.	.42	
The bond between us isn't what it used to be.	.56	
It's like there's a barrier between us now.	.73	
I don't feel about him the way I used to.	.67	
The bond between us is as strong as ever.	.63	
The dementia has brought us closer together emotionally.	.01	
I care for him, but I don't love him the way I used to.	.72	
Sharing Togetherness		.52
He's in a world of his own most of the time.	.28	
We face our problems as a couple, working together.	.46	
We still do things together that we both enjoy.	.23	
I only tell him what he needs to know.	.24	
Expression		.76
It makes me feel uncomfortable if he is affectionate towards me.	.52	
Sometimes I feel he invades my personal space.	.60	
I don't like it if he comes too close to me.	.68	

The aim in developing the BRCM was to generate a comprehensive single factor scale, rather than to establish a multi-factorial scale. However, as shown in table 2.3 the domains of the BRCM have acceptable internal consistency, except for the sharing togetherness domain, although, the individual items in this domain still contribute well to the overall scale.

PHASE 5 –Evaluation of the final version of the BRCM

In the last phase of the study, the final 26-item version of the BRCM was subjected to further evaluation in the form of an assessment of concurrent validity and of test-retest reliability. To assess the concurrent validity of the measure, the participants completed two measures that purport to measure domains similar to those included in the BRCM - the *heartfelt sadness and longing* subscale of 'Marwit-Meuser Caregiver Grief Inventory' (MMCG-I) (Marwit & Meuser, 2002) and 'The Closeness and Conflict Scale' (Schofield et al., 1997). It was difficult to find satisfactory measures to assess concurrent validity because there is no other questionnaire that measures relationship continuity. However, the two measures were selected because they appear to overlap with two of the domains of the BRCM. The *heartfelt sadness and longing* subscale of the MMCG-I measures the sense of loss and thus overlaps with the 'loss' domain of the BRCM; and the Schofield measure is meant to measure changes in feelings following the assumption of a caring role and so overlaps with the 'same/different feelings' domain of the BRCM.

The Closeness and Conflict Scale

The Closeness and Conflict scale (Schofield et al., 1998) has a total of six items, which are broken into two domains: "Closeness" and "Conflict". The closeness domain measures the compassion, love and closeness in the relationship and the conflict scale measures the conflict, tension and resentment. Participants are asked to rate whether each

item occurs 'less', 'the same' or 'more', following the onset of the caring role. The Closeness and Conflict scale has been used with carers of people with dementia (Schofield et al., 1998). Reliability data presented by Schofield et al. (1998) are reasonable: Closeness $\alpha = .73$ and Conflict $\alpha = .75$. The conflict items were reversed, thus a higher score on this scale suggests more closeness in the relationship.

Marwit-Meuser Caregiver Grief Inventory (MMCG-I)

The MMCG-I is a 50 item inventory with three subscales 1) Personal Sacrifice Burden 2) Heartfelt, Sadness and Longing and 3) Worry and Felt Isolation. The overall MMCG-I is used as a measure of grief of a spouse caregiver. The *heartfelt sadness and longing subscale* of the MMCG-I which is used in this research has a total of 15 items and is intended to measure the feelings of loss and sadness that can accompany caregiving. The *heartfelt sadness and longing* subscale was judged to represent the best overlap with the loss items of the BRCM. There is a five point Likert response 1 = strongly disagree 5 = strongly agree. The higher the score, the higher the levels of sadness and loss reported. Example items are "*I long for what was, what we had and shared in the past"* and *"I miss having someone to share my life with"*. Marwit and Meuser (2002) found that the measure has good internal consistency with an alpha level of .90.

Participants for the last phase of the study were recruited through Alzheimer's Society as previously described; ten participants were recruited in this manner. In addition participants were recruited via a NHS memory clinic in the West Midlands. These participants were contacted by the memory clinic manager prior to their partner's clinic appointment. Participants who expressed an interest in the research were given the participant information pack at the appointment (appendix C) and were given the choice

of reading the information sheet and completing the three questionnaires there and then, or taking them home and returning them in a stamped and addressed envelope. A total of 11 participants were recruited through the memory clinic. All participants were asked to indicate on the consent form if they agreed to be contacted again for test-retest purposes.

The re-test participants were asked to complete the BRCM for a second time to determine whether the BRCM is a stable measure or whether responses to it are affected by other fluctuating variables such as mood, fatigue or time of day. The duration between the completions was 1-2 weeks. As the re-test BRCM were completed and returned via post, definite information about the duration of the interval between the two completions was not available.

The final version of the BRCM was completed by 21 participants, and 14 of these participants completed the measure a second time for retest. The demographics of this sample can be seen in Table 2.1. Statistical analysis was conducted using the statistical package SPSS version 17. SPSS output tables for all statistical analyses are presented in Appendix F.

Missing data

The data were firstly checked to identify any missing data. There were no missing data for the BRCM or the Schofield measure. However, four participants had not completed item 8 on the MMCG-I – (*It hurts to put her/him to bed at night and realize that she/he is "gone")*. The missing data were replaced with the mean item score of that participant for the other items on the MMCGI that had been completed, and rounded up or down to the nearest whole number. The lack of missing data on the BRCM suggests that it may have reasonable user acceptability.

Table 2.4. Descriptive statistics.

Total	**Mean**	**Error**	**Min**	**Max**	**SD**	**Shapiro-Wilk**	**Sig**
BRCM Total	77	5.1	35	115	23.5	.950	.335
BRCM retest	77.9	7.3	35	115	26.4	.925	.293
BRCM-Same/different feelings	22	1.4	7	32	6.6	.960	.520
BRCM- Loss	6.8	.78	3	13	3.6	.851	.004
BRCM Same/different relationship	8.1	.88	3	15	4.0	.898	.032
BRCM Same/different person	17	1.5	7	13	7.0	.901	.036
BRCM Togetherness	11.4	.73	6	19	3.3	.963	.578
BRCM Expressed affection	10.6	.77	4	15	3.5	.925	.107
MMCG-I	49.4	3.0	21	71	13.9	.954	.407
Closeness & Conflict	11.5	.55	7	18	2.5	.963	.578
Background Challenging	13.3	.52	9	17	2.4	.941	.226
Background Support	11.7	.58	9	22	2.7	.670	.000

The distributions of all the measures were explored to highlight any outliers or irregularity in the data before any statistical analysis was completed. Table 2.4 shows the means, standard deviations and other descriptive information regarding the totals used in the analysis. As can been seen from Table 2.4, the total scores used in data analysis were all reasonably close to the normal distribution (as shown by the Shapiro-Wilk statistic) except for the *loss* subtotal on the BCRM and the *support* score. There were also no

outliers. Thus parametric statistics were considered appropriate, except for these two scores (analyses of which involved Spearman's rho).

Internal consistency

The BRCM was found to have good internal reliability with an overall Cronbach's alpha level of α = .94. Good internal consistency was also found in the re-test data (α = .96), suggesting good internal consistency. The analysis however did reveal that item 4 '*the dementia has brought us closer emotionally*' had a slight negative item-total correlation of -.025 on the first completion, but a good positive item-total correlation of +.46 in the re-test data. The original item-total correlation of this item in the 47 items version was .73. This item may require further analysis with a larger sample to establish whether it is satisfactory.

The overall alpha for the *heartfelt sadness and longing subscale* of the MMCG-I with this sample (N = 21) was α = .95. The Closeness and Conflict Scale had an overall alpha level of α = .78.

Test re-test reliability- intra-class correlation

To assess test-retest reliability, the intra-class correlation was calculated, using a two-way random model focused on single measures and absolute agreement (McGraw & Wong, 1996). This was 0.922 (95% confidence limits = 0.974 to 0.997; p <.001). Hence, participants' responses to the test items did not change substantially over time, revealing good stability.

Concurrent validity

To test for the validity of the BRCM, a correlation was conducted with two previously standardized measures (Closeness and Conflict Scale, and the MMCG-I). As the data were normally distributed, a Pearson's correlation was conducted. It was found

that the total of the BRCM has a significant correlation with both the MMCG-I (r =-.54, p< .01) and the Closeness and Conflict Scale (r = .43, p <.05). The direction of the relationship for the MMCG-I was negative, thus high scores from one of the measures is associated with low scores from the other. Thus higher scores on the BRCM, suggesting continuity, are associated with lower scores of loss and grief as measured by the MMCG-I. The significant correlation between the BRCM and the Closeness and Conflict Scale suggests that the higher the score on the BRCM measuring relationship continuity the higher the score for closeness in the relationship as measured by the Closeness and Conflict Scale.

The MMCG-I was expected to correlate specifically with the *loss* subscale of the BCRM, and the Closeness and Conflict Scale was expected to correlate specifically with the *same/different feelings* subscale. A Spearman's correlation was conducted between the MMCG-I and the *loss* items of the BRCM, as the distribution of the *loss* items was not normal. The correlation was significant (r = -.672 p < .01). Importantly, this correlation was higher than the correlation between the total BRCM score and the MMCG-I. This would be expected if the MMCG-I items overlap with the *loss* items on the BRCM more than with any other items on the BRCM.

A Pearson's correlation was conducted between the *same/different* feelings sub total of the BRCM and the Closeness and Conflict Scale. The correlation was significant suggesting that the two scales do measure similar constructs (r = .621, p < .01). Again, this correlation was higher than the correlation between the total BRCM score and the Closeness and Conflict Scale, which is consistent with the assumption that the Closeness and Conflict Scale overlaps specifically with the *same/different feelings* domain of the BRCM.

In summary, the results provided evidence of reasonable concurrent and divergent validity. There were large correlations between the two established measures and those domains of the BRCM hypothesized to overlap with the established measures, which provided evidence of concurrent validity for those domains of the BRCM. However, the correlations between the two established measures and the total score on the BRCM were more modest, which indicates that the BRCM is measuring something different and thereby provides evidence of divergent validity.

Relationship continuity and demographic variables

Neither gender nor age of the carer had a significant relationship with BRCM scores (t (20) = 1.0, p =. 32; and r = .18, p = .43, respectively). The duration between the overall relationship and continuity was found not to be significant (r = .26, p = .25). Neither was the duration of the dementia diagnosis and the total BRCM score (r = .01, p = .98).

Information was extracted from the information given by participants in the final sample (N = 21) to provide summary scores measuring firstly, the care needs and the challenging behaviour of the person with dementia and secondly, the support that the carers/people with dementia received (Table 2.1). The summary score of care needs/challenging behaviour was constructed using questions from the background questionnaire that related to disturbed sleep, distress and agitation of the spouse with dementia and needing assistance in dressing, eating and using the toilet. The support summary scores consisted of having day care services, sitting service, cares coming to the home and support from friends and family. It was found from the results of a Pearson's correlation that the level of care/challenging behavior did not have a significant relationship with the level of perceived continuity in the relationship (r = .30, p = .18).

Continuity and the amount of support received for caring was also not found to have a significant relationship (r =.12, p = .61).

Discussion

A 26 item questionnaire known as the BRCM was developed, and the results showed it to have good internal consistency, good test-retest reliability and good concurrent validity.

The BRCM aims to measure relationship continuity using the following domains: same/different relationship; same/different person; same/different feelings; sharing and togetherness; expression of emotion and attachment and finally loss. Initially 47 initial items were used, which were deemed to have good user acceptability and face validity by a focus group. After this the 47 item version of the BRCM was completed by 51 participants. Item analysis was used to reduce the number of items to 26. These 26 items showed good internal consistency. The internal consistency of the six domains is variable, however, the psychometric properties of the measure as a single factor scale to assess continuity were shown to be sound.

The final version of the measure was completed by 21 participants along with two other measures. Evidence of concurrent validity was provided by the fact that the *loss* subscale from the BRCM was found to have a large negative correlation with the *heartfelt sadness and longing subscale* of the MMCG-I; and the *same/different feelings* subscale was found to have a large positive correlation with the Closeness and Conflict Scale. Some evidence of divergent validity was provided by the fact that the total BRCM score had only modest correlations with the MMCG-I and the Closeness and Conflict Scale. Thirteen of the final sample completed the BRCM a second time and good test-retest reliability was obtained.

Demographic variables of the participants were also collected and used to investigate if they influenced the BRCM. The results of the analysis found that gender, age of the carer, the length of the couple's relationship and time since diagnosis did not have a significant relationship with the BRCM and thus relationship continuity. There was also no correlation between the BRCM and care needs/challenging behaviour or the BRCM and support needs. The lack of any correlation between the BRCM and time since diagnosis or level of care needs is potentially interesting because it is inconsistent with the suggestions of Hellstrom et al. (2007) that spouse carers move smoothly through phases of relationship change as the dementia worsens. It may, instead, be the case that there is considerable individual variation in terms of how quickly carers begin to feel a sense of discontinuity. Others factors may explain this individual variation, such as the personality of the carer and their perception of the caring situation. The influence of the prior relationship may also have an effected on the likelihood of the carer perceiving continuity in the relationship, as suggested by Morris, Morris and Britton (1988). However, these non-significant findings must be interpreted with caution as the total sample size was small.

Limitations

The main limitation of this research is the small participant numbers (N = 51 for the first sample; N = 21 for the second sample and N = 14 for the test-retest evaluation). The recruitment of participants for the research was difficult. Reasons for this may be the nature of the caring role and potential participants not having the time to give to the research. Halfway through the data collection there was also a national postal strike, which may have resulted in some of the completed questionnaires not being returned successfully. Recruiting through a big organisation such as the Alzheimer's Society was

anticipated to maximize the number of potential participants. However, access through this source was somewhat restricted because the organisation had received multiple requests for research participants and was concerned not to overload carers.

A larger sample would have been desirable as this would have allowed an analysis of the factor structure of the BRCM. Factor analysis could have been used to verify the assumptions that there are subscales within the overall scale, by looking at which items correlate most highly with each other. A larger sample size would have also provided more reliable findings and would have increased the confidence in the conclusions that the BRCM is in fact a reliable and valid measure of relationship continuity.

Another limitation is that the samples were probably not representative of the population of carers of spouses with dementia. Firstly the sample was self-selected. This could bias the sample, as participants who made the decision to complete the questionnaires may have traits or be in situations that could influence relationship continuity. Certain demographic groups were also under-represented in the sample, for example there was a lack of participants from ethnic minorities. Forbat (2003) explored reasons why carers in ethnic minorities may find access to services difficult. She discovered that the stigma associated with having a diagnosis of dementia can lead South Asian families to 'conceal' the troubles that their family member may be having for fear of the wider community perceiving that the person with dementia is 'crazy'. St. John (2009) reviewed the obstacles to the Asian community's accessing support for a family member with dementia. She discovered that dementia was understood differently from a western perspective and suggested that strong religious beliefs coupled with a scene of responsibility to care for a family member resulted in Asian families not actively seeking support out of their family unit. Furthermore, St John (2009) also suggested that the

stigma associated with dementia may lead to families hiding the symptoms. These cultural differences may have an impact on issues related to relationship continuity, and so it is important to recognize that the BRCM may not be valid when applied in other cultural settings. Further research would be needed to address the issue.

Another limitation of the BRCM is the limited involvement of carers in the construction of initial items. Although the items were drawn from interview transcripts there was no direct input into the construction and content of the items used. The focus group was able to comment and advise, but they were not invited to add their own items, and the transcripts from the interviews were not conducted with the aim of developing items for a scale. Greater involvement from carers in the development of items for inclusion in the scale may have produced a scale that was more accessible and more relevant to carers.

Further research

The psychometric properties of the BRCM need to be tested on a larger sample of spousal carers. A larger sample size would allow for increased confidence in the BRCM with regards to validity and reliability. A factor analysis could also be conducted with a larger sample to investigate the factor structure of the questionnaire. It also needs to be evaluated on a more representative sample. In particular, it needs to be evaluated in the context of spousal carers from different ethnic and cultural backgrounds.

Despite the limitations of the current evaluation, the BRCM shows promise as a measure of relationship continuity. As discussed in the Introduction, previous research on this issue has been qualitative. The BRCM provides a foundation for a quantitative approach to this issue.

Implications for clinical practice

It is important for clinicians to assess the relationship between the person with dementia and their spouse, and to consider how it may have changed and what impact those changes may have on both the carer and the person with dementia. In many services the emphasis is placed on the person with dementia and supporting the carer is only addressed when there is a possibility of carer breakdown. With the recent government guidelines highlighting the importance of a new deal for carers in dementia (Department of Health, 2009 & 2008; NICE, 2007; Department of Health, 2000), the carer's needs and the relationship should be given more attention by clinical services. The BRCM could be an effective tool in addressing these issues.

References

Alzheimers Society. (2007). *Dementia UK: The full report*: England.

Department of Health. (2008). *Carers at the heart of 21st-century families and communications-summary.* London: Department of Health.

Chesla, C., Martinson, I., & Muwaswes, M., (1994). Continuities and discontinuities in family members' relationships with Alzheimer's patients. *Family Relations, 43*(1), 3-9.

Department of Health. (2000). Carers and Disabled Children's Act. London: HMSO.

Department of Health. (2008). High quality Care for all: NHS next stage review Final Report. London: HMSO.

Department of Health. (2009). New Horizons: towards a new vision for mental health. London: HMSO.

Fleash, R. (1948). A new readability yardstick. *Journal of Applied Psychology*, 32, 221-233.

Forbat, L. (2009). Concepts and understandings of dementia by 'gatekeepers' and minority ethnic 'service users'. *Journal of Health Psychology, 8*(5), 645-655.

Goddard, R.D. III., & Villanova, P. (2006). Designing surveys and questionnaire for research. In T.L. Leong & J. Austin (eds.), *The psychology research handbook* (pp 58-97). Portland: Sage Publications.

Hellstrom, I., Nolan, M., & Lundh, U. (2007). Sustaining "couplehood": spouses' strategies for living positively with dementia. *Dementia, 6*(3), 383-409.

Kaplan, L. (2001). A couplehood typology for spouses of institutionalized persons with Alzheimer's disease: perceptions of "We"-"I". *Family Relations, 50*(1), 87-98.

Lewis, R.D.H. (1998). The impact of the marital relationship on the experience of caring for an elderly spouse with dementia. *Ageing and society, 18,* 209-231.

Marwit, S.J., & Meuser, T.M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimers Disease. *The Gerontologist, 42*(6), 751-765.

Murray, J. (1995). Social support and coping styles. In J. Murray (Eds.), *prevention of Anxiety and depressions in vulnerable groups* (pp 50-52). London: Gaskell.

Murray, J., & Livingston, G. (1998). A qualitative study of adjustment to caring for an older spouse with psychiatric illness. *Aging and Society, 18*, 659-671.

Morris, L., Morris, R., & Britton, P. (1988). The relationship between intimacy, perceived strain and depression in spouse caregivers of dementia sufferers. *British Journal of Medical Psychology, 61*, 231-236.

NICE, (2007). Dementia: guidelines on supporting people with dementia and their carers in health and social care. London: HMSO.

Office for National Statistics. (2001). London: HMSO.

Ott, C., Sanders, S., & Kelber, T. (2007). Grief and personal growth experiences of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementia. *The Gerontologist, 27,* 798-809.

Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L.M., Belle, S.H., Burgio, L., Gitlin, L., Coon, D., Burns, R., Gallagher-Thomson, D. & Stevens, A. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist, 42,* 589-602.

Schofield, H.L., Murphy, B., Herrman, H.E., Bloch, S., & Singh, B. (1997). Family caregiving: Measurement of emotional well-being and various aspects of the caregiving role. *Psychological Medicine, 27,* 647-657.

St. John, T. (2004). Hidden Shame- A Review of the Needs of Asian Elders with Dementia and their Carers in a Kent Community. *Journal of Integrated Care, 12*(3), 20-26.

Vitaliano, .P., Zhang, J., & Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129,* 946-972.

Walters, A. (2008) Unpublished doctoral thesis. *A qualitative study exploring spouse caregivers' understanding of and responses to partners with a dementia*. University of Birmingham.

Wijngaart, M., Vernooij-Dassen, M., & Felling, A. (2007). The influences of stressors, appraisal and personal conditions on the burden of spousal caregivers of persons with dementia. *Ageing and Mental Health, 11,* 626-636.

Wright, L. (1993). *Alzheimer's Disease and Marriage*. Newbury Park: Sage Publications.

Paper 3

Executive summary – Public domain paper

Measuring Continuity in Spousal Relationships

Gemma Fisher 2010

Construction and Initial Validation of a Measure of Relationship Continuity when Caring for a Spouse with Dementia.

Background

Lewis (1998) suggests that the responsibility for community-based care of older adults with dementia is usually given to the spouse. Having to adapt to changes in a relationship, that are wrought by dementia, whilst continuing to care for a partner can be stressful and can be perceived as both positive and negative for the carer (Baikie, 2002).

Research conducted by Walters (unpublished thesis, 2008) at the University of Birmingham explored six female carers' understanding of their husbands and their responses to partners. The findings of the qualitative study suggested that changes in the carers' experience of closeness and distance in the relationship varied across individuals. Some experienced discontinuity and distance in their relationships but for others the experience was regarded as a continuation of their longstanding relationship. Discontinuity in the relationship seemed to be associated with negative emotions of caring, such as guilt and feelings of entrapment.

The aim of this research was to design an instrument that could reliably measure the relationship continuity in the spousal relationship, when a spouse has dementia.

Method

Transcripts from a previous study investigating relationship continuity were used to generate 47 items for the Birmingham Relationship Continuity Measure (BRCM) (Walters, unpublished thesis, 2008). A focus group of 4 carers was used to review the measure and offer face validity. A total of 51 participants, who all cared for their spouse that had dementia, completed the BRCM and statistical analysis was used to reduce the BRCM to 26 items. Another 21 participants then completed this version of the BRCM and two other measures that assess similar constructs (Closeness and Conflict Scale:

Scofield et al., 1997 & Marwit and Meuser Caregiver Grief Inventory: Marwit & Meuser 2002). Participants were recruited through both the Alzheimer's Society West Midlands and a NHS memory clinic.

Results and discussion

Reliability analysis revealed that the BRCM is reliable in measuring continuity in spousal relationships. Comparing the BRCM total score to the Closeness and Conflict Scale and the MMCG-I resulted in two significant correlations. The findings suggested that the higher the BRCM score, measuring relationship continuity, the higher the score for closeness and the lower the score for loss and grief. The participant's gender, age, support that they received and the amount of challenging behaviors that the person with dementia demonstrated did not have an effect on the BRCM score.

The BRCM is a reliable and valid measure. However, there are a few limitations. The first is the low number of participants that completed the BRCM. Having more participants would have allowed for a different type of statistical test which could have enabled more confidence to be place in the results found. Also as no ethnic minorities completed the BRCM more research would need to be carried out to see if the BRCM is a good way of measures relationship continuity for carers from different cultures. Overall the BRCM needs to be given to a bigger sample.

References

Baikie, E. (2002). The impact of dementia in marital relationships. *Sexual and Relationship Therapy*, 17(3) 289-299.

Lewis, R.D.H. (1998). The impact of the marital relationship on the experience of caring for an elderly spouse with dementia. *Ageing and society, 18*, 209-231.

Walters, A. (2008) Unpublished doctoral thesis. *A qualitative study exploring spouse caregivers' understanding of and responses to partners with a dementia*. University of Birmingham.

APPENDIX A

Ethical approval from NREC and R&D

APPENDIX B

Focus group interview schedule (17/04/2009)

Obtain informed consent

Introduce the topic (changes in spouse relationships when one had dementia)

Do they like the Likert scale or the Yes/No response?

Asked to fill in the questionnaire.

Acceptability of the scale and the items in the questionnaire.

Do the items seem to related to the topic

Readability and comprehension of the items within the questionnaire.

Does the questionnaire allow the respondents to express their view adequately?

Are any of the questions confusing?

Comprehension of the instructions given and what would they change. Did the instructions make you want to fill in the questionnaire?

Any negative effects that the questionnaire had on the participants

Any suggests for improvements, removing items or additional questions.

APPENDIX C

Information packs send to or given to potential participants.

(There were four versions of these packs- depending on the phase- all were very similar.)

THE UNIVERSITY OF BIRMINGHAM

"Devising a self-report measure of relationship continuity for family carers in dementia".

Project Information Pack

This pack should contain:

- Project covering letter
- Project explanation sheet
- Two copies of Consent form
- Background Information Questionnaire
- Relationship Questionnaire
- Schofield Closeness and Conflict Scale
- Marwit-Meuser Caregiver Grief Inventory
- Pre-paid return envelope

School of Psychology
Edgbaston
Birmingham
B15 2TT
Tel: 0121 414 4897
Tel: 0121 414 4909

Project Covering Letter

Dear Carer,

We are writing to inform you of a new project that is being carried out at the University of Birmingham that you and your partner are invited to take part in. We are writing to all carers of partners who have dementia via the National Health Service (NHS) in Wolverhampton, and carers of partners who have association with the Alzheimer's Society, to ask for your help with our research. We have passed this letter and the attached information sheet and consent form to the respective support group or Alzheimer's Society staff and they have sent them on to you on our behalf.

Before you decide whether or not you and your partner would like to take part we want to explain why the research is being carried out and what it will involve. Enclosed is an information sheet that outlines the aims of the study. Please take the time to read this information. If you feel you are unclear about any aspect of the study, or have any questions do not hesitate to contact Gemma Shercliff at the above address.

We are interested in learning more about your relationship with your partner following a diagnosis of dementia. We are particularly interested in what changes and what continues to be the same. We want to be able to design a questionnaire to aid in understanding these changes and help us to highlight carers who may need support in the future. To do this will involve completing the enclosed questionnaires and returning them to me at the University of Birmingham in a pre- paid envelope.

We are very aware that you may have completed questionnaires in the past or spent time participating in projects or talking to researchers. If so, we thank you for your participation in previous projects, your participation is greatly appreciated and has been critical in informing research in this area. However, in order for our research to continue to be useful, it is important that we hear from as many carers as possible so that we can get the broadest possible picture. We therefore hope that you will continue to provide your support for this research.

It is possible that this research may stir up your feelings about your current situation. Should this be the case and you feel you need extra support, then please raise this with your Support Group co-ordinator or someone else involved in your partner's care. Alternatively you can also contact the Alzheimer's society (tel: 0121 474 3800 or email: BirminghamAndSolihull@alzheimers.org.uk). If you feel in urgent need of help then please see your GP who will be able to arrange appropriate services for you.

If, after reading the project explanation sheet, you would like to take part in this study then please fill in the attached consent form and questionnaire and return it to the research team in the envelope provided. If you need any assistance in completing the questionnaires or require bigger print, please do not hesitate to contact Gemma Shercliff on the above address.

Thank you for taking the time to read this letter. We look forward to hearing from you.

Yours sincerely,

Gemma Shercliff
Trainee Clinical Psychologist

Dr Jan Oyebode
Consultant Clinical Psychologist

Dr Gerry Riley
Clinical Psychologist

Project Explanation Sheet

Project

The following list tells you about this study and what you need to do in order to take part in the study. However, if you need any further guidance, or have any questions, please do not hesitate to contact the research team by email, phone, or post to the address shown on the first page.

This research is being undertaken by Gemma Shercliff as part of her doctoral studies at the University of Birmingham.

Please read this information carefully before deciding whether you wish to take part in the study:

Background

- Previous research has shown that changes may occur in relationships when a spouse has a diagnosis of dementia.
- Currently there is no formal way to measure these potential changes.

Why is this research important?

- It will provide us with a questionnaire that can be used in future research to help us understand how relationship changes impact on the lives of carers
- It will help us to devise better ways of aiding carers in the future.

What will happen in the research?

If you agree to take part in the research you will be asked to fill in four questionnaires about you and your relationship with your partner (please see attached). You will also be asked if you would agree with being approached again to fill in one of the questionnaires a second time. If this is something you would like to do, it would involve supplying your name and address. You would be contacted within two weeks of completing the first questionnaires. The questionnaires should take no longer than 30 minutes to complete in total.

Assistance

If you decide to take part in this research but feel you require assistance in completing the attached questionnaire, this can be arranged. All you need to do is contact Gemma Shercliff at the above address.

Consent

It is up to you whether or not you take part in the study. If you do decide to become involved then consent will be required. On the consent form provided you will be asked to sign a declaration to partake in the study. If you wish to be contacted again to complete a second questionnaire you will be required to leave your name and address on this form.

Withdrawal

Once you have granted consent you can request that your questionnaires are withdrawn from the study at any time up to 6 weeks after you have completed them, without giving a reason. Your questionnaires will then be removed and destroyed. This will not restrict you and your partner's access to other services and will not affect their right to treatment.

Confidentiality

Your confidentiality will be ensured, initial contact is being made through others and only after consent has been obtained will your name be collected. If published, information will be presented without reference to your name or any other identifying information. All questionnaires will be stored in a secure place. Your name will not be written on any of the questionnaires and you will only be identifiable by a number known only to the researchers.

What to do with the questionnaires?

You have a couple of options for completing the questionnaires, you may want to take them away, complete them and then return them to me via the self addressed envelope, or you may wish to fill in the questionnaires during a coffee morning where a member of the research team will be present. The choice is completely up to you.

At the end of the study

A summary of the project findings will be circulated to everybody involved who wishes to see a copy.

Review

The University of Birmingham, School of Psychology Research Ethics Committee has reviewed and approved the study. The study will also be approved by the local National Health Service (NHS) ethics committee.

For further information please contact:

Dr Jan Oyebode, at;
School of Psychology
University of Birmingham
Edgbaston
Birmingham
B15 2TT

tel: 0121 414 4909
e-mail – J.R.OYEBODE@bham.ac.uk

The consent form

You should find two copies of the consent form in this pack. If you decide to take part in this study it is essential that you complete and sign the copy of the consent form and that your return these signed documents together with the background information questionnaire. The other copy is for you to keep for your information.

Checklist for people interested in taking part in the study:
Items to be returned to the research team

- A signed copy of the consent form
- A completed background information questionnaire
- The relationship questionnaire.
- The Marwit-Meuser Caregiver Inventory

- The Schofield Closeness and Conflict Scale

Items you may wish to keep

- The project explanation sheet
- A copy of the consent form
- The project cover sheet which contains information about the research team's contact details

Should you wish to take part in this study your participation will be greatly appreciated as your assistance is extremely important in guiding research in this area.

Thank you for taking the time to read this information.

Consent Form

Please initial the boxes

I confirm that I have read and understood the project explanation sheet for the above study and have had the opportunity to ask questions. ☐

I understand that participation in the study is voluntary and that I am free to end my involvement at any time, or request that the data collected in the study be destroyed, without giving reason. ☐

I agree to the my participation of the above study ☐

I agree to be contacted again, for further participation* ☐

*Please complete the information below

Participant's name ……...

Contact address and telephone number …….…….…….

……..……

……..

All Participants need to sign here.

Participants signature …….. Date……

FOR OFFICE USE ONLY

Signature of researcher …… Date…….

Background Information Questionnaire

Please circle or write your response to these questions concerning

The following questions are about you:			
1	What is your gender:	**Male**	**Female**
2	How old are you?	**Years _____**	
3	How long have you been together as a couple?	**Years _____ Months _____**	
4	How long has your partner had the diagnosis of dementia?	**Years_____ Months _____**	
5	If you know the type of dementia that was diagnosed please tick the appropriate box opposite.	Alzheimer's disease ☐ vascular or multi-infarct dementia ☐ mixed dementia ☐ Lewy Body ☐ Fronto-temporal dementia (FTD) ☐	
6	How would you discribe your ethnicity: (please tick the box opposite that best suits you).	White British ☐ Asian ☐ Black ☐ Chinese ☐ Mixed - White and Asian ☐ Mixed - White and Black ☐ Other mixed background ☐ Any other ethnic background ☐	
7	How would you describe your religion? (please tick the box opposite that best suits you).	Christian ☐ Jewish ☐ Muslim ☐ Buddhist ☐ Sikh ☐ Hindu ☐ Other religion ☐ No Religion ☐	
The following questions are about the support you may receive:			
8	Do you receive any support from family, friends or neighbours in looking after your partner?	**Yes**	**No**
9	Do carers come in on a regular basis to help you in looking after your partner?	**Yes**	**No**
10	Does your partner receive any respite care or a sitting service?	**Yes**	**No**
11	Does your partner attend a day care service?	**Yes**	**No**

The following questions are about your role as a carer:			
12	How long have you been caring for your spouse?	**Years_____ Months _____**	
13	Do you see your friends as often as you used to?	**Yes**	**No**
14	Are you able to take a break from caring for a few hours if you need to?	**Yes**	**No**
15	During the day, are you able to leave your partner unsupervised for half an hour or more while you get on with things in another part of the house?	**Yes**	**No**
16	Is your sleep often disturbed by your partner?	**Yes**	**No**
17	Does your partner sometimes become distressed and agitated?	**Yes**	**No**
18	Does your partner sometimes ask the same question over and over again?	**Yes**	**No**
19	Does your partner ever hit out at other people?	**Yes**	**No**
20	Does your partner ever do or say things in public that draw attention to himself/herself?	**Yes**	**No**
21	Is it sometimes difficult for you to persuade your partner to do things?	**Yes**	**No**
22	Do you have to assist your partner to get dressed?	**Yes**	**No**
23	Do you have to assist your partner to eat?	**Yes**	**No**
24	Do you have to assist your partner to use the toilet?	**Yes**	**No**

APPENDIX D

Final version of the BRCM (female carer version)

Birmingham Relationship Continuity Measure

Instructions

Please read the questions on the following pages carefully and then circle the response option on the right that best expresses your view (as shown below). If you change your mind about your answer, simply cross it out and circle the response that you feel best expresses your view. Please answer ALL questions as honestly as possible.

Examples

1	Caring for my partner can be difficult	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

1	Caring for my partner can be difficult	Agree a lot	~~Agree a little~~	Neither	Disagree a little	Disagree a lot

1	It's like there's a barrier between us now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
2	We face our problems as a couple, working together.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
3	The dementia has brought us closer together emotionally.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
4	It makes me feel uncomfortable if he is affectionate towards me.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
5	I care for him, but I don't love him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
6	We still do things together that we both enjoy.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
7	I feel like his carer now, not his wife (partner).	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
8	He's a shadow of his former self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
9	I don't feel about him the way I used to.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
10	I only tell him what he needs to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

11	Despite all the changes, he's still his old self.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
12	The bond between us isn't what it used to be.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
13	I miss having someone to share my life with.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
14	Sometimes I feel it's like living with a stranger.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
15	I feel shut off from him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
16	I feel I've been grieving for him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
17	Despite all the changes, our relationship has remained much the same as it was.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
18	Compared to how he used to be, he's a different person altogether now.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
19	I don't like it if he comes too close to me.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
20	I feel like I've lost the person I used to know.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
21	I don't feel I really know him any more.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
22	The bond between us is as strong as ever.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
23	He still has many of the same qualities that first attracted me to him.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
24	He's in a world of his own most of the time.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
25	It doesn't feel like a partnership any more	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot
26	Sometimes I feel he invades my personal space.	Agree a lot	Agree a little	Neither	Disagree a little	Disagree a lot

APPENDIX E

Measures used for concurrent validity

Marwit-Meuser Caregiver Grief Inventory

This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g. Alzheimer's disease). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1-5 to the right using the answer key below. It is important that you respond to all items so that the score are accurate.

		Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree
1	I miss so many of the activities we used to share	1	2	3	4	5
2	I have this empty, sick feeling knowing that my loved one is "gone".	1	2	3	4	5
3	I feel terrific sadness.	1	2	3	4	5
4	This situation is totally unacceptable in my heart.	1	2	3	4	5
5	I long for what was, what we had and shared in the past.	1	2	3	4	5
6	I could deal with other serious disabilities better than this.	1	2	3	4	5
7	I'm angry at the disease for robbing me of so much.	1	2	3	4	5
8	It hurts to put her/him to bed at night and realize that she/he is "gone"	1	2	3	4	5
9	I feel very sad about what this disease has done.	1	2	3	4	5
10	I feel powerless.	1	2	3	4	5
11	It's frightening because you know doctors can't cure this disease, so things only get worse.	1	2	3	4	5
12	I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2	3	4	5
13	I can't contain my sadness about all that's happening.	1	2	3	4	5
14	I wish this was all a dream and I could wake up back in my old life.	1	2	3	4	5
15	I've had a hard time accepting what is happening.	1	2	3	4	5

Schofield Closeness and Conflict Scale

In the table below, please rate, by ticking one of the three options, how much the emotions listed have changed or stayed the same in your relationship, since you started caring for your partner.

Closeness	**Less**	**The Same**	**More**
Compassion			
Love			
Closeness			
Conflict	**Less**	**The Same**	**More**
Tension			
Conflict			
Resentment			

APPENDIX F

SPSS output tables for Empirical Paper

DESCRIPTIVE STATISTICS

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean		Std. Deviation	Skewness	
	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Statistic	Std. Error
BRCMTotal	21	80.00	35.00	115.00	76.9048	5.13805	23.54550	-.211	.501
MMCGTotal	21	50.00	21.00	71.00	49.4286	3.04691	13.96271	-.375	.501
CloseConflictTotal	21	11.00	7.00	18.00	11.5238	.55899	2.56162	.512	.501
BRCMLossTotal	21	10.00	3.00	13.00	6.8095	.78261	3.58635	.675	.501
BRCMSameFeelTotal	21	25.00	7.00	32.00	22.0000	1.43427	6.57267	-.571	.501
ChallengeTotal	21	8.00	9.00	17.00	13.3333	.52251	2.39444	-.267	.501
SupportTotal	21	13.00	9.00	22.00	11.7619	.58515	2.68151	2.946	.501
BRCMSameRelTotal	21	12.00	3.00	15.00	8.1905	.88538	4.05733	-.048	.501
BRCMSamePerTotal	21	23.00	7.00	30.00	17.9048	1.54289	7.07039	-.120	.501
BRCMShareTotal	21	13.00	6.00	19.00	11.4286	.72562	3.32523	.486	.501
BRCMExpreTotal	21	11.00	4.00	15.00	10.5714	.77019	3.52947	-.398	.501
BRCMRetest	14	80.00	35.00	135.00	77.9231	7.34276	26.47471	-.391	.616

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
BRCM	.158	21	.182	.950	21	.335
MMCG-I	.179	21	.078	.954	21	.407
Closeness/Conflcit	.133	21	.200*	.963	21	.578
BRCM-Loss	.256	21	.001	.851	21	.004
BRCMsame/dif	.152	21	.200*	.960	21	.520
Challenging	.159	21	.178	.941	21	.226
Support	.274	21	.000	.670	21	.000

a. Lilliefors Significance Correction

*. This is a lower bound of the true significance.

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
BRCMRetest	.170	13	.200*	.925	13	.293

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
BRCMTotal	.158	21	.182	.950	21	.335
BRCMSameFeelTotal	.152	21	.200*	.960	21	.520
BRCMLossTotal	.256	21	.001	.851	21	.004
BRCMSameRelTotal	.148	21	.200*	.898	21	.032
BRCMSamePerTotal	.195	21	.036	.901	21	.036
BRCMShareTotal	.128	21	.200*	.963	21	.578
BRCMExpreTotal	.183	21	.065	.925	21	.107

a. Lilliefors Significance Correction

*. This is a lower bound of the true significance.

Reliability ANALYSIS

BRCM

Reliability Statistics

Cronbach's Alpha	N of Items
.942	26

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Q2	74.4762	522.162	.604	.940
revQ3	74.0476	515.948	.563	.940
Q4	73.9524	554.548	-.025	.946
Q5	73.0000	527.400	.424	.942
Q7	73.3333	503.333	.662	.939
rev 8	72.8095	532.662	.334	.943
Q9	74.3333	500.533	.750	.938
Q10	74.9048	514.490	.626	.940

Q11	73.5714	508.857	.659	.939
Q12	74.5714	523.257	.459	.942
rev13	73.5714	489.857	.844	.937
Q14	74.0476	509.148	.609	.940
Q15	74.7143	506.214	.695	.939
Q16	74.0952	491.890	.844	.937
Q17	73.7619	499.990	.729	.938
Q18	74.6190	525.048	.533	.941
rev19	74.0000	497.900	.784	.938
Q21	74.3810	499.548	.822	.937
Q22	73.4286	523.157	.457	.942
Q23	74.5714	508.057	.610	.940
Q24	73.6190	509.748	.648	.939
rev25	73.1905	516.062	.683	.939
rev26	72.9524	517.648	.622	.940
Q27	74.7619	540.390	.261	.943
Q28	74.1905	492.962	.896	.936
Q29	73.7143	526.714	.350	.943

RE-TEST RELIABILITY BRCM

Reliability Statistics

Cronbach's Alpha	N of Items
.957	26

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
R2	75.3077	652.397	.629	.956
revR3	74.6923	646.731	.690	.955
R4	75.4615	681.603	.461	.957
R5	74.1538	655.141	.575	.956
R7	74.3077	642.064	.715	.955
revR8	73.9231	672.410	.425	.957
R9	75.4615	638.436	.791	.954
R10	75.7692	649.026	.641	.956

R11	74.3077	640.564	.735	.955
R12	75.0000	669.667	.374	.958
revR13	74.6923	625.397	.833	.954
R14	75.1538	650.808	.587	.956
R15	75.6923	643.064	.663	.956
R16	74.8462	627.974	.875	.953
R17	75.0769	621.577	.916	.953
R18	75.6923	664.064	.555	.956
revR19	75.1538	631.641	.836	.954
R21	75.2308	637.526	.811	.954
R22	74.1538	652.808	.664	.955
R23	75.6154	646.256	.640	.956
R24	74.6923	646.897	.688	.955
Revr25	74.3846	659.423	.651	.956
revR26	74.0000	653.667	.641	.956
R27	75.6154	677.423	.418	.957
R28	75.0769	627.744	.897	.953
R29	74.6154	663.423	.458	.957

Same Different Relationship

Item-Total Statistics

	Corrected Item-Total Correlation
Q9	.619
rev19	.708
Q28	.928

Reliability Statistics

Cronbach's Alpha	N of Items
.866	3

Loss

Item-Total Statistics

	Corrected Item-Total Correlation
Q15	.643
Q18	.517
Q23	.824

Reliability Statistics

Cronbach's Alpha	N of Items
.799	3

Same Different Person

Item-Total Statistics

	Corrected Item-Total Correlation
Q10	.583
rev13	.845
Q16	.880
Q24	.638
Q21	.800
rev26	.533

Reliability Statistics

Cronbach's Alpha	N of Items
.892	6

Same Different Feeling

Item-Total Statistics

	Corrected Item-Total Correlation
Q17	.424
Q14	.595
Q2	.734
Q11	.674
rev25	.634
Q4	.008
Q7	.723

Reliability Statistics

Cronbach's Alpha	N of Items
.803	7

Expression

Item-Total Statistics

	Corrected Item-Total Correlation
Q5	.523
Q29	.602
Q22	.677

Reliability Statistics

Cronbach's Alpha	N of Items
.764	3

Sharing Togetherness

Item-Total Statistics

	Corrected Item-Total Correlation
Q27	.282
revQ3	.460
rev 8	.257
Q12	.244

Reliability Statistics

Cronbach's Alpha	N of Items
.516	4

Closeness and Conflict Scale

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
S1	9.3333	5.033	.432	.768
S2	9.3810	5.448	.589	.751
S3	9.5714	4.557	.545	.741
revS4	9.9048	4.290	.562	.738
revS5	9.6667	4.733	.601	.728
revS6	9.7619	4.490	.533	.745

Reliability Statistics

Cronbach's Alpha	N of Items
.779	6

Marwit-Meuser Caregiver Grief Inventory - heartfelt *sadness and longing subscale* scale

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
MM1	45.8571	168.829	.685	.943
MM2	46.6190	174.948	.631	.944
MM3	45.8095	173.962	.739	.942
MM4	46.0952	174.190	.699	.942
MM5	45.9048	165.890	.854	.938
MM6	46.6190	171.148	.635	.944
MM7	46.0476	166.848	.772	.940
MM8	47.1429	177.629	.482	.947
MM9	45.5714	169.957	.823	.940

Reliability Statistics

Cronbach's Alpha	N of Items
.945	15

MM10	45.8571	171.929	.681	.943
MM11	45.4286	175.557	.658	.943
MM12	46.1429	167.229	.744	.941
MM13	46.6667	169.933	.688	.942
MM14	46.0476	160.048	.861	.938
MM15	46.1905	169.262	.762	.941

Correlations

Correlations

		BRCMTotal	MMCG-I Total	Closeness Total
BRCMTotal	Pearson Correlation	1	-.542*	.428
	Sig. (2-tailed)		.011	.053
	N	21	21	21
MMCG-ITotal	Pearson Correlation	-.542*	1	-.197
	Sig. (2-tailed)	.011		.393
	N	21	21	21

*. Correlation is significant at the 0.05 level (2-tailed).

Marwit-Meuser Caregiver Grief Inventory - heartfelt *sadness and longing subscale* scale

X BRCM- LOSS ITEMS

Correlations

			BRCM Loss	MMTotal
Spearman's rho	BRCM Loss	Correlation Coefficient	1.000	-.672**
		Sig. (2-tailed)	.	.001
		N	21	21

**. Correlation is significant at the 0.01 level (2-tailed).

Closeness and Conflict Scale X BRCM Same/different feelings

Correlations

		SSTotal	BRCM Loss
SSTotal	Pearson Correlation	1	.621**
	Sig. (2-tailed)		.003
	N	21	21

**. Correlation is significant at the 0.01 level (2-tailed).

Gender x Totals of the BRCM

Group Statistics

	gender	N	Mean	Std. Deviation	Std. Error Mean
BRCMTotal	male	8	83.6250	24.70938	8.73609
	female	13	72.7692	22.78579	6.31964

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
BRCMTotal	Equal variances assumed	.115	.738	1.027	19	.317	10.85577	10.56568	-11.25845	32.96998
	Equal variances not assumed			1.007	14.006	.331	10.85577	10.78226	-12.26897	33.98051

Severity of dementia and BRCM

Correlations

		ChallengeTotal	BRCMTotal
ChallengeTotal	Pearson Correlation	1	.306
	Sig. (2-tailed)		.178
	N	21	21

Support of dementia and BRCM

Correlations

		BRCM	SupportTotal
BRCM	Pearson Correlation	1	.119
	Sig. (2-tailed)		.607
	N	21	21

Age and BRCM

Correlations

		age	RCTotal
age	Pearson Correlation	1	.183
	Sig. (2-tailed)		.428
	N	21	21

Duration together as a couple and BRCM

Correlations

		couple	BRCM
couple	Pearson Correlation	1	.261
	Sig. (2-tailed)		.253
	N	21	21

Duration of Illness and BRCM

Correlations

		BRCM	lengh
BRCM	Pearson Correlation	1	-.007
	Sig. (2-tailed)		.976
	N	21	21

APPENDIX G

Information to Authors- Aging and Society